DOCUMENT RESUME

ED 305 430 CE 051 934

AUTHOR	Mehrotra, Chandra, Ed.; And Others
TITLE	Family Caregiving. A Manual for Caregivers of Older Adults.
INSTITUTION	College of St. Scholastica, Duluth, Minn.
REPORT NO	ISBN-0-9621122-0-8
PUB DATE	88
NOTE	99p.; Manual partly funded through a grant from the Arrowhead Regional Development Commission's Aging Program.
AVAILABLE FROM	College of St. Scholastica, 1200 Kenwood Avenue, Duluth, MN 55811 ($13.00; 50 or more: $10.00 each).
PUB TYPE	Guides - Non-Classroom Use (055)
EDRS PRICE	MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS	Adult Children; *Aging (Individuals); *Family Caregivers; Family Involvement; Family Life; Family Problems; Frail Elderly; Guides; *Older Adults; Stress Management

ABSTRACT

This manual provides caregivers with practical knowledge and suggestions that could be of help to them in this important role. Chapter 1 gives an overview of the volume and tells how to use it. Chapter 2 identifies who caregivers are, what they do, and what changes have taken place in their lives since they became caregivers. Chapter 3 begins with a discussion of the sources of stress, its symptoms and stages, and its consequences and then describes techniques to reduce stress or its effects. Discussion in chapter 4 focuses on communication in the family, including such topics as information sharing, changing nature of relationships, need for support systems, and patterns of communication. Chapter 5 focuses on techniques for aiding communication with those with impaired hearing or vision, stroke, or neurological deficits. Chapter 6 describes important changes in the body and major age-related diseases. Chapters 7 and 8 provide information about the changing nutritional needs of older adults and about different types of exercise. Topics in chapter 9 concern the psychology of aging. Chapter 10 describes the various types of living arrangements in terms of the needs of the older people they accommodate. Chapter 11 covers legal and financial matters. The final chapter introduces a variety of agencies and their services that may be helpful in meeting the needs of caretakers and their older relatives. Recommended readings and references for each chapter are listed. (YLB)

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FAMILY Caregiving

A Manual for Caregivers of Older Adults

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FAMILY CAREGIVING

A MANUAL FOR CAREGIVERS OF OLDER ADULTS

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This manual is made possible in part under the Federal Older Americans Act through a grant from the Arrowhead Regional Development Commission's Aging Program.

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First Edition

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Library of Congress Catalog Card No. 88-72175

ISBN O-9621122-0-8

Printed in the United States of America

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Chapter 1

What Is in This Manual for You?

Chandra Mehrotra
College of St. Scholastica

What Is Informal Caregiving?

A great amount of care for older adults is provided by their spouses, daughters, sons, daughters-in-law, sons-in-law, friends, and neighbors. Those who provide such care play an extremely important role in the lives of older people and are referred to as "informal caregivers." The term "informal caregiving" refers to unpaid care provided to an older person who has some degree of physical, mental, emotional, or economic impairment which limits independence and necessitates ongoing assistance. Indeed, it is the availability of this informal care that is often crucial in ensuring that older people can maintain their preferred life style within the community. Here are some typical situations:

- **Mrs. Reed, 62, found herself torn between two telephone calls. In one she heard about her 83-year-old father who was feeling sick. In the other she heard her daughter's tired, sad voice pleading for her presence because her two small children were sick.**

- **Delores, a schoolteacher, and Jackie, a registered nurse, are two unmarried sisters who live with and share responsibility for their 79-year-old widowed mother who is blind and paralyzed by a stroke.**
- **Last year, Lucy, 58, took a leave of absence from her job to care for her terminally ill husband who died shortly thereafter. A month later her severely impaired 88-year-old mother moved in, and Lucy has never returned to work.**
- **Tom and Marie have cared for Tom's father, Bill, in their home for the past three years. Bill, a stroke victim, also experiences periodic bouts with depression. The family, including their three children, share the caregiving responsibilities.**
- **John and Mary have been providing care to Laila, John's mother, who has been living with them since she had a mild stroke a year ago. This summer Mary had to go out of state to conduct a workshop, and their plan was that her husband John would join her. Because of a sudden turn in his mother's health, John decided not to leave town so that he could take care of his mother. Fortunately, their 21-year-old daughter, Candy, came home from college, and the two were able to share the caregiving role.**

As these examples show, caregiving becomes a family affair in many households, involving members of different ages. Family members help each other depending upon their needs, abilities, and other demands on their time. Sometimes we serve as caregivers and at other times we are care receivers. This theme of reciprocity in caregiving, which is shown in the illustration at the beginning of this chapter, is referred to as the "circle of caring."

While the type of care provided by informal caregivers like yourself depends upon the disability level of the care receiver, almost all of you provide some degree of assistance or emotional support through visiting, telephoning, or helping the older person work through problems. In addition, most of you are involved in providing a broad range of services such as transportation, shopping, housekeeping, meal preparation, financial management, personal care assistance, and help with health care needs. Thus, most of you devote a significant amount of time and energy in providing care to an elderly relative or friend.

Why Did We Publish This Manual?

Recognizing that these caregiving responsibilities require new knowledge and skills on your part, the College of St. Scholastica developed an educational program to address the needs of caregivers like yourself. While the program has met the needs of many caregivers in our region, we feel that we may not have reached a large number of caregivers who are unable to attend the educational sessions. It is this group of caregivers that we plan to reach through this manual.

How Can This Manual Be of Help to You?

How can you shoulder the caregiving responsibility without depleting yourself emotionally, physically, or financially? How can you maintain other roles and at the same time be able to do all that needs to be done for the person you are caring for? Our goal in preparing this manual is to provide you with some practical knowledge and suggestions which could be of help to you in this important role as a caregiver.

In selecting the topics for this manual, we were guided by caregivers like yourself, by our experience in conducting the educational sessions, and by people who are knowledgeable in the study of aging. While we have tried to anticipate the needs of all of you who may read this manual, we are well aware of the fact that all caregivers are not alike. Your situations, your backgrounds, and your needs differ a great deal. Each chapter of the manual may not, therefore, be of equal interest to all of you. Furthermore, the chapters need not be read in any specific order.

While most of the chapters address you, the caregiver, the discussion in some of the chapters will be applicable to you as well as to your older relative or friend. Thus, when we use the pronoun "you," we mean the caregiver and when we use the term "care receiver" or "care recipient," we are talking about the older person who receives in-home care. Also, since care recipients and caregivers are both males and females and since it is awkward to read **he/she** or **his/hers,** we have alternated the pronouns **he (him, his)** and **she (her, hers).** Therefore, if we use **he, him,** or **his** in one section of a chapter, we would use **she, her,** or **hers** in another section.

We hope that as a result of reading the manual you will be able to:

- better understand age-related changes.
- identify the various resources in the community which may be of help to you in dealing with the problems and issues related to caregiving.
- be aware of the various challenges and issues related to caregiving and the manner in which you would handle them.
- take some practical steps to lessen the day-to-day strains.
- make appropriate choices in a variety of situations related to caregiving.

What Topics Are Included in the Manual?

In order to enable you to achieve the above objectives, we have included the following chapters in this manual.

Chapter 1: What Is in This Manual for You? In this introductory chapter we give you an overview of the entire volume, tell you why this manual was prepared, and how you may use it to get the most out of it.

Chapter 2: Being a Caregiver. In this chapter we identify who the caregivers are, what they do, and what changes have taken place in their lives since they became caregivers. Other topics covered in this chapter include recognition of one's own needs, and ways in which to find resources which would be helpful.

Chapter 3: Managing Stress Effectively. This chapter begins with a discussion of the sources of stress, its symptoms and stages, and its consequences, and then provides a discussion of the techniques which can help reduce stress and/or its effects. It emphasizes the importance of finding time for yourself while you are involved in the caregiver role.

Chapter 4: Communication in the Family. Included in this chapter is a discussion of topics such as information sharing, changing nature of relationships, need for support systems, and patterns of communication.

Chapter 5: Techniques for Aiding Communication. While in the previous chapter we emphasize the importance of communication in maintaining relationships, our focus in this chapter is on devices that are helpful in facilitating or aiding communication with those who have impaired hearing, impaired vision, stroke, or neurological deficits.

Chapter 6: Changes in the Body. This chapter describes the important changes in the various body systems and also includes a discussion of major age-related diseases.

Chapter 7: Nutritional Needs. This chapter provides you with valuable information about the changing nutritional needs of older adults and gives you specific suggestions on how to meet these needs.

Chapter 8: Exercise for Fitness. This chapter provides information about different types of exercise. Specific exercises are explained to enable you to establish your own personal exercise program.

Chapter 9: Psychology of Aging. Topics covered in this chapter include changes and losses, therapeutic environments, perceptions of control, memory, dementia, depression, and bereavement. Valuable suggestions are offered to enable you to develop a better understanding of the care receiver's feelings and emotions.

Chapter 10: Living Arrangements. In this chapter, we have described the various types of living arrangements in terms of the needs of the older people that they accommodate. Suggestions are provided that may be helpful in choosing among the various possibilities.

Chapter 11: Legal and Financial Matters. Topics covered in this chapter include various types of insurance programs, legal issues related to wills and probate, and a brief discussion about conservatorships and guardianships.

Chapter 12: Where to Get Help. This chapter introduces you to a variety of agencies and their services which may be helpful to you in meeting your own needs and those of your older relative.

The major guideline we used in selecting the above topics was that the information be useful in meeting your needs and those of the older adult you care for. Thus, the chapters in the manual describe age-related changes, provide suggestions on how to develop a better understanding of the older person and his needs, and enable you to see what improvements or changes might be possible.

How to Use This Manual

The table of contents. Since this manual has been designed as a self-study guide, we thought it would be helpful to you if we included some suggestions on how to get the most out of it. Before you start reading the chapters, we suggest that you look through the table of contents so that you know what topics are included in the manual, which of these chapters you would like to read.

Survey the chapter. After you have decided to read a particular chapter, begin by paging through the chapter and reading the summary at the end of the chapter. This should not take much time and will show you the main ideas discussed in the chapter. This will also help you to think about the ideas as you read them later.

Reading, questioning, and reciting. Now begin to read. Turn the first heading into a question, if it is not already written as one. This will arouse your curiosity and thereby increase your understanding. It will bring to mind information you already know, thus helping you to understand that section more quickly. The questions will also make important points stand out in your mind. When you are reading the section, try to answer the question. This will make you an active learner, searching for the answer to the question that you had created from the section heading. Having read the first section, try briefly to recite the answer to your question. Use your own words and cite an example from your caregiving situation. Continue reading in this way until the entire chapter is completed.

We realize that some of you may not be used to reading "technical" material. While we have tried to keep the chapters relatively short and nontechnical, some topics may still seem difficult to understand. It would be helpful if you study such chapters in smaller units and at a slower pace.

We suggest that you pay particular attention to the material presented in the boxes included in the chapters. They contain important practical information for you.

Active learning. Active involvement in which you ask and answer questions and relate the material to your caregiving experiences is an effective learning approach. It may also be helpful to discuss important points from the chapters with your friends or with the care receiver.

In a number of chapters in this manual, you will find questions, checklists, and other exercises. Try to become an active learner and see how many of these questions you can answer and how many points you can recite after you have read the chapter. In order to get the most out of the material covered in the chapters, it may be worthwhile to read the chapters or portions of chapters several times. Rereading a chapter helps in developing a better understanding of the important points.

Recommended readings. Obviously a manual like this cannot cover all the issues which may be of interest to individual caregivers. Also, the space limitations did not allow us to include all the details on the topics that we have discussed. We have, therefore, included a list of recommended readings at the end of the manual. Organized by chapters, the list provides information about available books from which you can learn more about topics related to caregiving and aging. Check with your local library or bookstore about their availability.

Tell Us About Your Experiences!

While we have presented practical knowledge and suggestions that may be helpful to you in your role as a caregiver, we are aware of the fact that many of you have learned a great deal as a result of your experiences in caregiving. We are sure you have already discovered ways of handling situations and coping with difficulties. Our hope is that you would be willing to share these ideas, experiences, anecdotes, and suggestions with us and with other caregivers. Please write to us. We would very much like to hear from you! Write to:

Informal Caregivers Project
Department of Psychology
College of St. Scholastica
Duluth, Minnesota 55811

We recommend that you next read chapter 2 on *Being a Caregiver*, but after that, other chapters may be selected in any order according to your interests and needs. We believe that you will find something of value to you in the manual for use in your important role as a caregiver! Best wishes and good reading!

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Chapter 2

Being a Caregiver

Sheila Vedder
College of St. Scholastica

Caring Is Giving

> You give but little when you give
> of your possessions.
>
> It is when you give of yourself
> that you truly give.
>
> Kahlil Gibran

Providing care to someone in need of help can be rewarding. Indeed, millions of family members and friends are caregivers. Estimates are that from 80% to 90% of care is given to older adults by family members. It is only a *myth* that we abandon older members of our family!

A great deal has been written about the burdensome role of caregivers, but the positive aspects of caregiving are often overlooked. We feel it is just as important to understand the opportunities and benefits associated with providing care to an older person. This chapter is, therefore, directed to a discussion of both positive and negative aspects of caregiving. Other topics included are: the role and responsibilities of caregivers, respite care, and relationships. Thus, upon completing this chapter, you will be able to answer the following questions:

- What are the feelings that I experience as a caregiver?
- What are the changes that have occurred in my life since becoming a caregiver?
- How can I build upon positive aspects of caregiving, including enriching relationships with others?

Who Are Caregivers?

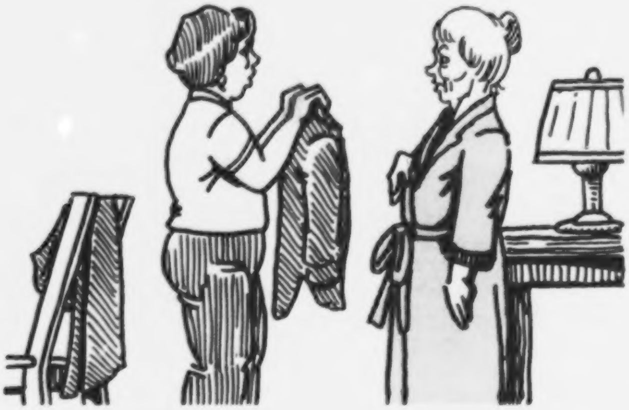
Although the majority of older adults are healthy and independent, many individuals who reach their late seventies, eighties, and nineties have one or more chronic illnesses. These conditions require varying degrees of assistance, much of which is provided by family members.

The majority of caregivers are women (72%). About 13% of husbands and only 9% of sons are primary caregivers. Daughters-in-law also often provide care to their in-laws on a regular basis. You may be surprised to know that for the first time in history, women spend on the average more years providing care to a parent than providing care to their children!

Although the typical caregiver is in his or her late 40s and 50s, many caregivers (about 35%) are 65 years or older. You might be one of the many people who are a part of four generations of living relatives. If so, you may be concerned for and providing care to an older adult and to younger generations at the same time. This is sometimes referred to as the "sandwich generation." Today the average married couple has more parents than the number of children they have. Thus, providing some type of support or "parent care" is a very real possibility for many middle-aged adults.

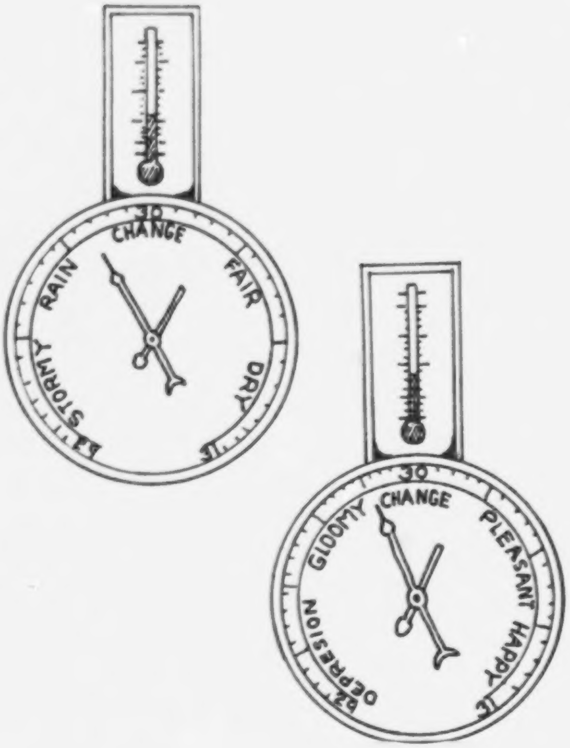
The Caregiver's Role

Depending upon the illness or disability of the care recipient, you may need a variety of new skills for providing **physical care**. These skills may include taking a temperature or blood pressure reading, draining a catheter, or giving an enema. Other tasks might involve turning or positioning, lifting, and transferring your loved one in bed or into a wheelchair. Dressing, bathing, and feeding may also require special skills on your part. These tasks are only part of the job for many caregivers.



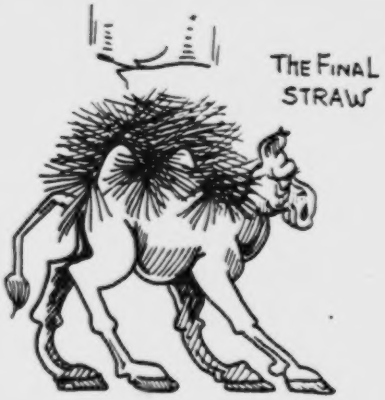
Emotional support can be as time-consuming and difficult to provide as physical care. The emotional strain can affect you whether the older adult is living with you, in their own home, or in a nursing home. In spite of moments of frustration, anger, or even exhaustion, providing love and support can be satisfying. For many caregivers it is a combination of many different feelings. You could compare feelings about the role of caregiver to the weather: when it is warm and sunny (when things are going well), you may feel good and optimistic about what you are doing; but, when it's cold or raining (things are not going so well), you may feel angry, resentful, or depressed.

For some caregivers negative feelings are acted out in the form of **abuse**. It is important for you to clearly understand your responsibility to the person for whom you provide care. The **Vulnerable Adults Act** was originally passed in 1980 to protect individuals 18 years or over who are unable or unlikely to report abuse or neglect because of mental, emotional, or physical impairment. This Minnesota law defines the "caretakers'" responsibilities, types of abuse and neglect, and reporting procedures. You should be aware of the various types of abuse such as physical, emotional, sexual, and verbal abuse. Insufficient food, shelter, and health care or inadequate supervision are also forms of neglect or abuse. The results of abuse are not always visible, but the harmful effects can be serious. Abuse or neglect can be prevented or stopped. If you or someone you know are abusing the person you are caring for, GET HELP. Call a social worker, police department, physician, or clergy. If *you* are being abused by the person to whom you are providing care, it is also important to seek help.



Identify Your Feelings

Sometimes it is difficult to identify just how we feel about the situations we find ourselves in and the challenges we are given. Associating or attaching a word to your feelings is a good way to start to understand how you feel about being a caregiver. The following box contains a list of feelings that you may be experiencing. Go through the list and circle the feelings that apply to you.



HOW DO YOU FEEL ABOUT BEING A CAREGIVER?

needed
hopeful
sad
content
forgiving
useless
courageous
enthusiastic
angry
useful
aware
cynical
thoughtful
trapped

content
capable
hopeless
secure
forgetful
frustrated
appreciated
healthy
confused
overworked
intelligent
unloved
helpful
honest

open-minded
depressed
happy
proud
lonely
optimistic
dedicated
strong
disoriented
stressed
knowledgeable
guilty
stimulated
accepted

curious
logical
satisfied
tolerant
tired
pessimistic
loved
fearful
disliked
lost
scared
forgiven
faithful
burdened

After completing this checklist, take the opportunity to look over the list and try to determine specific actions or events that create your positive or negative feelings. How can the positive feelings be increased? How can the negatives be reduced or turned into a positive? How you feel about your role as a caregiver may be related to many things. Two areas are especially critical: (a) How much of your day is occupied in caregiving tasks? (b) How do you view your role as a caregiver? If your loved one needs minimal care and supervision, your responsibilities may not be as overwhelming as they are for someone who provides total care. Nevertheless, as discussed in the next box on **respite care**, all caregivers should have others who can relieve them from time-to-time of their caregiving responsibilities.

RESPITE CARE

Respite care is short-term substitute care to allow temporary relief for you, the caregiver. This "time out" allows you to do the things that you need to revive and refresh yourself. Respite care can be provided in the home, at an adult day care center, or in a nursing home. Some people receive respite care several hours per day while others obtain respite care for a week or two while they go on vacation. Many caregivers prefer that respite care be provided outside their home to allow them (the caregiver) precious time alone in their own home.

Respite care and other supportive services are not luxuries. These services are essential for you in maintaining your effectiveness and in reducing the stress of being a caregiver. If you would like to learn more about community resources such as respite care, read Chapter 12 on *Where to Get Help*. Realizing that you are not alone, that there are others involved as formal and informal caregivers, is helpful in keeping a healthy perspective.

Changes in Your Life as a Caregiver

Many changes may have taken place in your life since you've become a caregiver. Some of the changes may be good and others not so good. Here are some examples to help you think about changes that have happened to you:

- Caregiving may provide you an opportunity to do some things with your parent or spouse that you haven't done in the past.
- You may have developed different interests or hobbies due to the change in your schedule or to different demands on your time.
- You may have developed new friendships that wouldn't have evolved had you not become a caregiver.
- Your values, interests, and goals for your future may have changed.
- Sometimes when people begin to provide care to their spouse or frail parent, they begin to reflect upon their own aging and even their mortality.
- Other changes that may have occurred include having less privacy, fewer vacations, and less time to visit with friends or becoming active in your church or club.

It may be helpful to make a list of the changes that have occurred since becoming a caregiver. List both the negative and positive aspects of being a caregiver. The list may enable you to see where your greatest strengths are as well as areas in which you are vulnerable and in need of help or improvement.

After completing the list, review it. What are some specific changes that have occurred in your life that are especially positive or negative? What are some ways in which you could increase positive aspects of your life? How can the negative areas be reduced or turned into positive? The next chapter on *Managing Stress Effectively* may be extremely useful by providing ideas that will help you build positive, life-enriching activities into your everyday life.

Relationships

The quality of our relationships can influence how we feel. Let us take a look at some of the changes that can occur in relationships as a result of being a caregiver.

Care for your spouse. Sometimes caregivers become confused about the new relationship with their spouse. The familiar, intimate companionship with your mate may have become more one-sided, with you giving care and support but receiving less in return. It can be painful to provide care and not be able to cure illness or disability. How you anticipated growing old together may be very different from how your life is today. It may be helpful to talk to your spouse or someone you feel close to about your feelings about getting older.

Parent caring. Adult children may have difficulty in taking care of their parent(s), because they were on the receiving end for so many years. Sometimes, it may seem as if you and your parent(s) have reversed roles. Of course, it really isn't that way. Your parent will always be deserving of love and respect as an adult.

Family care. Sometimes caring for a parent disrupts relationships between husbands and wives and other children in the household. Asking for help, knowing your limitations, and taking time out for yourself and other family members will be helpful in maintaining other relationships inside and outside of the family.

Other relationships. There may be changes in your relationships with friends. Some friends that don't understand the time and involvement required as a caregiver may not seem as interesting or pleasant to be with as they once were. Having a wide variety of people to talk to and care about can be helpful. There are many different kinds of friendships. One person can never provide all that we need in a relationship, nor can you provide it to them. Be flexible, and do have a few close friends that you can talk to about anything.

You may also have more contact with health care providers, social service agencies, legal, and financial consultants. Although the services are needed, at times it can be frustrating or difficult to work with some individuals. If your contact with providers creates more frustration or confusion than help, take the initiative to investigate other options.

Building a Support System

Regardless of our age, we need different things from a variety of people. Do you remember the saying, "You can't be all things to all people?" Do you believe it? If you do, then you need to realize you can't be all things to one person either. It's important that the person for whom you are caring interacts with others and receives love and encouragement from a variety of people. It's also essential for you. Everyone needs a support system.

A support system consists of a number of individuals from several areas of life including family members, friends, clergy, physicians, nurses, social workers, etc. A caregiver support group is also an excellent source of support for you.

There are many kinds of support. Support can be assistance in providing the physical needs of the person you are caring for. That is, assistance in lifting, toileting, or bathing, as well as assistance with transportation, chore services, or meal preparation.

Support may also mean that someone is providing information, guidance, or advice. When we need support the most, the people we expect to be there or want to be there may not be available. On the other hand, some individuals may be "too" available. Advice is often easy to get—even when it's not asked for. Have you ever heard the saying, "Some people stay longer in an hour than others do in a month?" If unwanted advice or upsetting suggestions are frequent, you may need to learn how to be assertive. Being assertive can be helpful in reducing your negative feelings as well as getting your needs met. See Chapter 3 on *Managing Stress Effectively* for more information about this topic.

We all need others to support us by reminding us that we are loved, to help us build our self-esteem, or to be a companion and friend—someone to be with us in our pain and sorrow as well as in our joy. Caregivers are often angry or disappointed with family members for not providing assistance or praise. When all efforts fail to get family members involved, then it is wise to include other outside helpers—both professional and informal. It is also important to give yourself praise. It has been said, "You are your own worst enemy." In other words, we are often much too hard on ourselves. It is important to take pride in the fact that we are doing the best we can with the information and abilities we have.

Summary

Identifying feelings, doing the best we can within our limitations, and joining together with others can help us from feeling overwhelmed by our caregiving responsibilities. Remember that you are not alone . . . there are millions within the circle of caring!

Chapter 3

Managing Stress Effectively

David Swenson
College of St. Scholastica

Taking Care of Yourself

In this chapter we will discuss the sources and effects of stress and suggest a variety of actions to reduce your level of stress and to help maintain the quality of your life. As you read the following scenarios, notice the variety of feelings that the caregivers are experiencing.

- **Margaret worries each time she goes to the store and leaves Hank alone and unsupervised. He tends to wander and has gotten lost even a block from home. Margaret finds herself increasingly tied to home and isolated from her usual activities and friends.**
- **Fred and Janet have been helping Fred's mother manage her finances for the last five years. Now she accuses them of changing her ledger books, hiding her money, even stealing from her. They feel hurt and frustrated, uncertain how to deal with her accusations.**
- **Susan, a nurse, works the night shift at a local hospital. She chose this shift so she could be home during the day with her three children. Recently, Susan's mother has needed help with household chores, transportation to doctor appointments, and physical therapy three times a week for a chronic back problem. Susan's willingness to provide help to everyone without adequate rest and self care is leaving her physically exhausted and short-tempered with family members and friends.**

These scenarios have in common the "stress" that can result from difficulties related to the caregiver role. In order for you to give care to someone else, **you must also take care of yourself**. Without such self care, your chances of being affected by stress are greatly increased, perhaps to the point of disability yourself! To manage your stress more effectively, there are several things to be understood about stress and your response to it.

Most often one becomes a caregiver out of necessity. It is not one of the jobs for which you were trained or expected to take. It just happened. The result is the same: the demands of caring for another person, while disregarding one's own needs, result in a wearing away of the caregiver physically, psychologically, socially, and spiritually.

Sources of Caregiver Stress

There is a wide variety of "stressors" (sources of stress) that are often present in caregiving relationships. Some are physical, such as the tiredness resulting from long hours without respite (time out), or physical strain from assisting someone out of bed or with bathing. Other stressors are inconveniences resulting from special diets, inability to control the bladder or bowels, and medication schedules. There are also worries about the person's condition, concerns about how medical bills will be paid, and frustration about medical treatments not being as effective as hoped. Perhaps the most difficult are the relationship changes between the caregiver and the older person. With the older person's increasing dependency, the caregiver has less time for personal activities, hobbies, and spending time with others.

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The condition of the older person can be a major source of stress if considerable supervision is required by the caregiver. For example, in diseases involving mental deterioration the caregiver may be faced with suspiciousness and accusations, mood swings and irritability, as well as endlessly repeated questions. They must continually supervise the person in order to avoid wandering, losing or hiding things, or leaving unattended lit cigarettes, hot stoves and irons. There can also be the embarrassment at neighbors or visitors being offended by outbursts of profanity, inappropriate sexual behavior, unpleasant odors, or even striking out at others.

Caregivers can become "burned out" if the demands of a stressful situation are too great. It is important to emphasize that burnout is not the inevitable outcome to caregiving. While caregiving is certainly not easy, it is most often provided out of love and commitment to the older person. Many aspects of caregiving can be fulfilling and can result in personal growth for both the giver and receiver.

Stages of Stress

Many people equate stress with burnout. The term "burnout" conjures a cartoon image of a startled-looking character, soot-covered and crisp around the edges, after having escaped a fire or handled a bomb. Actual burnout from stress seldom happens so suddenly. In fact, burnout is more like the final stage in a long reaction to stress in which the caregiver may collapse in exhaustion. While the effects of stress gradually accumulate over time and can result in a severe outcome, there are many turning points in which stress can be successfully managed.

Stage I. The first stage of the stress process can be called the "honeymoon" period. The decisions you make and the expectations you have about your new caregiving role set the stage for later developments. Growing out of the very best intentions, you may become overcommitted by trying alone to meet all the needs of the older person. You can end up being overburdened if you set unrealistic goals or do not look at the consequences of long-term disability or mental deterioration. At this stage, the "setup" for later stress can go unnoticed because you feel strong and enthusiastic. If the older person's illness is very brief or if others are involved in sharing the caregiving, you might not move into Stage II.

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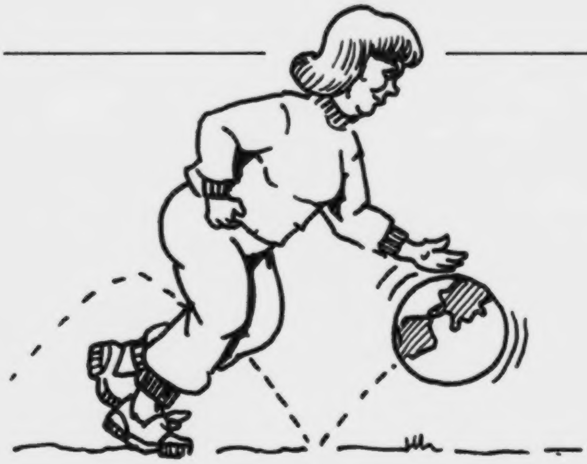
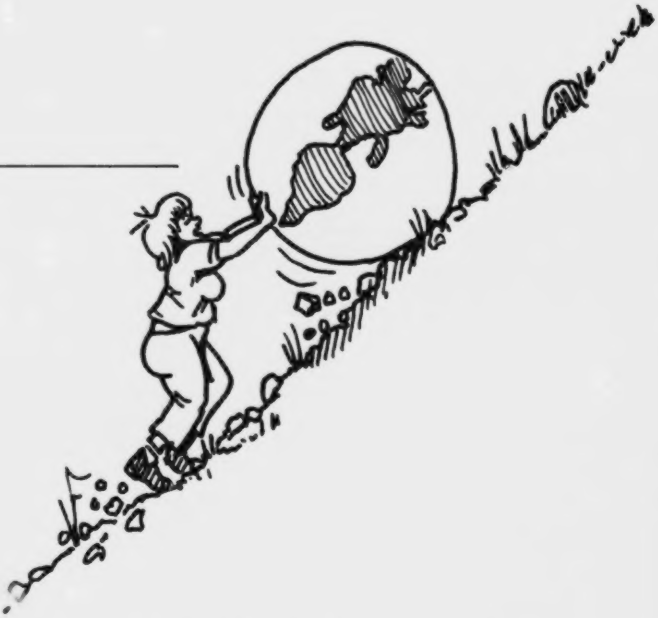




Stage II. The transition from first to second stage of stress occurs when high hopes, well-intentioned efforts, and best laid plans are not sufficient to cope with a difficult caregiving situation. Your relationship with the older person can become strained because of long hours of caregiving, lack of improvement in their condition, or your increased awareness of his deterioration. You sometimes sacrifice your personal satisfactions, activities, and friendships in order to provide the care to which you have committed yourself. At this stage you may be aware of a growing sense of isolation, resentment, or even grief over losses in your life. Your distress may be compounded by feelings of guilt that you are not "supposed to" feel resentment. You may feel frustrated and "penned in" and engage in brief arguments with the older person. Minor signs of stress may appear: increased smoking and drinking, headaches, irritability, worry, eating larger or lesser amounts of food, upset stomach, and increase in colds due to lowered immune resistance. It is often these discomforts that lead many caregivers to reassess their commitment, seek counseling or support groups, or attempt to manage their stress more effectively. Unfortunately, some caregivers may ignore these early warning signs and even increase their efforts to take sole responsibility for caregiving.

Stage III. This stage occurs when you become aware of how stressed you feel. You may feel trapped by guilt or obligation, with no obvious or acceptable sources of relief in sight. While you still love and cherish the person you are caring for, such feelings are often mixed with longings for "the old days" prior to the disability and are complicated with feelings of bitterness, sadness, and possibly depression.

If the older person has a deteriorating or terminal condition, the caregiver may experience "anticipatory grief." This sorrow is over awareness of the gradual and eventual loss of the relationship with the person. While such grief is normal, it too often goes unresolved. Instead you may attempt to avoid such thoughts, believing that you are betraying your commitment by thinking about loss and death. You may become very isolated at this stage and have limited contact with others. Common reactions include feeling cheated by life, being stuck in a daily routine, and showing signs of depression. Inactivity and worry may lead to noticeable weight loss or gain, stomach problems, headaches, sleep disturbance, acne, or general aches and pains. In conversations with others, you may be preoccupied with complaining. It is at this stage that your own health concerns may motivate you to seek help, or that friends and family may encourage you to examine your involvement.

Stage IV. The final stage of the stress response is a cumulative result of increasing pressure and demands. Hopefully, you will have examined your stress coping before you reach this stage. If not, it is at this point that you may be showing signs of your own limitations and, possibly, of physical and emotional disability. Frustration and depression may reach a point where you are no longer able to care for the disabled person, yet your intense involvement may not allow you to see the consequences. The pressure can become so great that you may have thoughts of running away, of over-medicating yourself with alcohol or tranquilizers, or even of considering violence to yourself or to the person you are caring for. Appearing trapped and hopeless, you may feel socially isolated, spiritually drained, believing there are no supports or resources available.

Fortunately, the above stages of stress don't occur overnight—it may take months or even years. There are many points at which you can restore yourself before stress is out of control or debilitating.

Checking Your Stress Level

Taking on the role of caregiver usually requires changes in other aspects of a person's life. Activity and schedule changes, a new member to the household, or shifting priorities all require that we adjust somehow. The more changes like these you experience over a relatively short period of time (a few months to a year), the more likely you are to have a stress reaction. Remember that stress symptoms can be as minor as worry, poor sleep, occasional headaches, frustration, and muscle tension, or as serious as ulcers, depression, and severe anxiety. Many of these symptoms could also be signs of a physical disorder. Therefore, if you are feeling pressure or are experiencing stress symptoms, be sure to check with your family doctor.

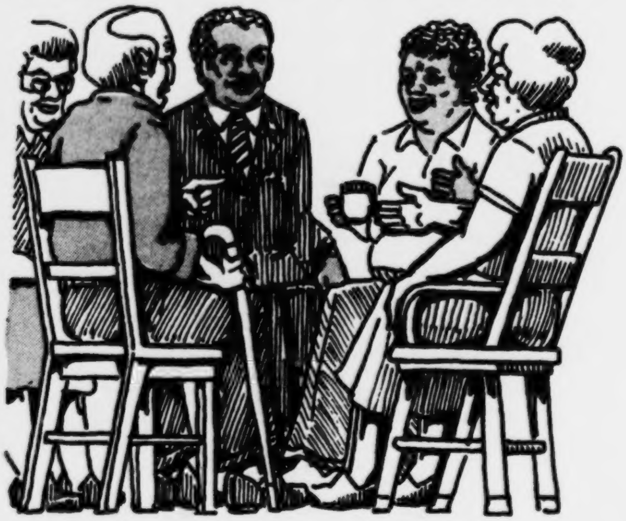
Stress Management Activities

Although there is no single method that works for everyone, there are hundreds of techniques that are used for managing stress. Rather than attempting to find and practice a perfect method—which probably doesn't exist anyway—it may be more useful to examine your lifestyle and find a variety of ways in which to reduce stress.

Below are suggestions that can be used to decrease stress. If you feel that you are too busy or don't have the time to do some of the following exercises or if you are feeling too desperate to try these activities, it may be a sign that another form of help to reduce stress is needed. If this is the case, discuss it with your family physician or other health care provider.

Be informed. Talk with health professionals and do plenty of reading and talking with others about the older person's medical condition. This will allow you to set goals based on what is known about the disease or disorder. For example, you don't have to take anger personally when you realize that a person who is depressed by her disability often expresses frustration by being irritable. You may be less stressed when you know what signs and behaviors to expect. Health practitioners (especially health educators), support groups, bookstores, and your local library can suggest sources of information.

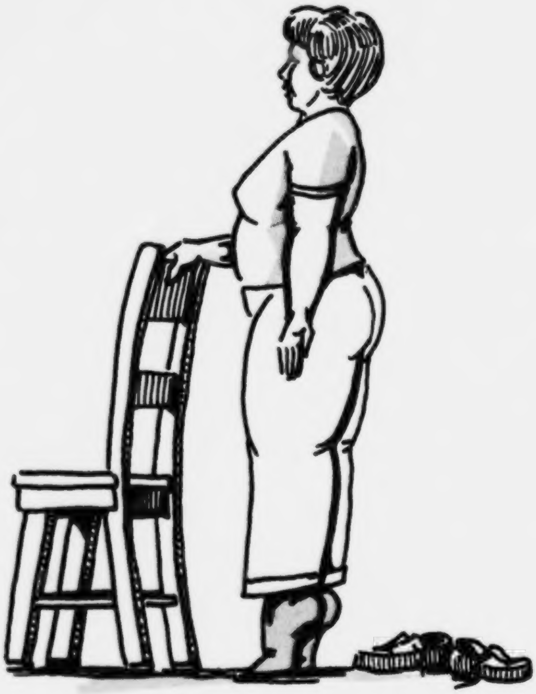
Express yourself. It is important to put your feelings into words and "clear the air" of emotions that build up if kept inside. It may be difficult to find such a release when the older person is a source of the feelings or is unable to listen or respond due to his condition. Find someone with whom you can share your frustrations, resentments, hopes, and satisfactions. Close friends, relatives, clergy, a support group or counselor may be extremely helpful.



Eat a balanced diet. Stress burns up greater than normal amounts of energy which may leave you listless, especially if the same stress has lessened your appetite. Make sure to regularly eat a balanced diet, including plenty of water. Be careful of the temptation to overuse vitamins and dietary supplements. If you have special dietary needs, check with a registered dietitian to help you plan your diet. Practical information on this topic is in Chapter 7 on *Nutritional Needs.*

ORANGE JUICE
MILK
MILK
COFFEE

Exercise. Under stress it is extremely important to stay active: long periods of sitting or being confined to a house can make you feel and think sluggishly. Regular exercise, even for brief periods, can release tension, improve efficiency of your heart and lungs, help stabilize your appetite, improve sleep, and provide a positive diversion for your thoughts. Exercise can consist of brisk walking, biking, swimming, jazzercise, cross-country skiing, or yoga. If you have not exercised for a long time, are out of shape, or have your own medical concerns, check with a health professional to find the exercise that is best for you. Chapter 8 on *Exercise for Fitness* has more information on this topic.



Learn to relax. "Relaxation" does not mean sitting in front of the television or just taking a walk. Those leisure activities do not really quiet the mind and body. Giving yourself a break from thinking and doing can help you recharge your energy. While there are many sophisticated techniques you can learn for relaxation from books, tapes, or a counselor, there are several things listed in the following box that you can do on your own.

HOW TO RELAX

- Schedule "protected time" where you will not be interrupted for 10-20 minutes. Make sure others understand that this time is as private and essential to you as sleeping, bathing, and using the bathroom.
- Sit in a comfortable chair or lie down. If you tend to go to sleep rather than remain relaxed, you may want to try a straight backed chair.
- Loosen any constricting clothing such as shoes, belt, tie, or glasses.
- Give yourself permission for a time out: "This is my time to relax and take care."
- Take a deep breath. As you inhale, say to yourself, "I can . . . ," and as you exhale complete the sentence by saying, ". . . feel relaxed." Repeat this a few times as you breathe slowly and comfortably.
- Start at the top of your head and imagine that waves of relaxation are moving gradually from your head all the way down your body. You may want to imagine the sensation of your arms and legs becoming heavy and warm with relaxation. Some people enjoy imagining the sunlight is soaking into their body and melting away tension and worry. Others like the image and sensation of clear water cleansing the "cobwebs" of tension or inactivity away. Experiment in order to find an image that is most interesting for you.
- Notice the rhythmic rising and falling of your breathing. Perhaps notice the warm pulsation of your heartbeat in your hands and feet as you relax more deeply. If other thoughts intrude, just come back to your breathing. This is your time to relax and take care.
- When you are deeply relaxed, you might consider using your imagination again for a "mini-vacation." Visualize yourself walking along a warm beach, or drifting like a cloud, or walking through a meadow of wildflowers. Use all your senses to make your vacation quite vivid: seeing, smelling, noticing temperature and texture, and even tasting.
- When you are ready to resume your daily activities, take another deep breath, saying to yourself, "I can wake up refreshed and alert and carry my relaxation with me."

Be assertive. Many people confuse assertiveness with aggressiveness. Assertiveness means standing up for your own rights, while aggressiveness is violating the rights of others. In the caregiving role, protecting yourself from becoming overextended and overburdened is good insurance that you will feel good and be able to provide quality care to the older person. Assertive behavior may mean that you will insist on having "protected time" where there will be no interruptions, or that you will have a social life with friends. It may mean that you will refuse to accept blame or accusations from relatives when you know that you are doing your best. You may decide to demand that other family members share part of the responsibilities, including: provide transportation, cover medication costs, or even write or phone more often. It's important to be direct when you want something. Others may think that they are being supportive, or that you are so strong that you do not need help. Let them know exactly what the situation is and precisely what you need. Stating something in an assertive manner can feel awkward at first. This may be a good opportunity to rehearse with a friend what you want to say to someone else.

Time management. Find ways where routine activities can take less time, be made simpler, or be delegated to someone else. For example, if meals are a problem use plastic tablecloths, smocks, and paper plates. Consider providing rent-free housing to a college student majoring in nursing, physical therapy, psychology, or social work in exchange for a few daily hours of supervision, cooking, or housework. Put your chores in a priority, taking the most important first, so each day you have a sense of accomplishment.

Build your self-esteem. When no one else is available to give you praise for your efforts, compliment yourself! Each day start out by saying an encouraging statement you need to hear to keep up your spirits. At the end of each day, review events and praise yourself for something you did or learned. Recognize things that you are good at and of which you are proud. Finally, don't keep your successes a secret from others. Especially if you are in a support group, share your insights and accomplishments.

Socialize. In a caregiving position it is all too easy to become cut off from friends and activities. Stay involved or seek out others if you have become isolated. The next box offers some suggestions for staying involved with others.

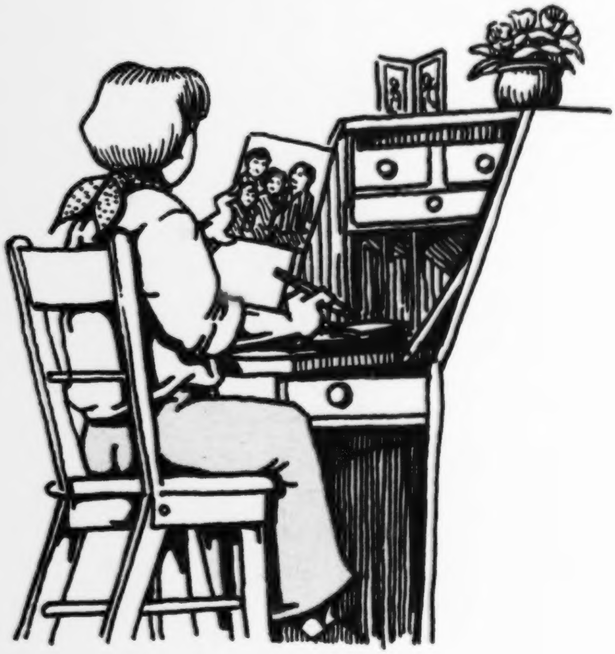
Discover meaning. Hardship is much more difficult to endure when it feels meaningless, unfair, and you have the question, "why me?" or "what's the purpose in all this?" It is important to find meaning so that the situation can be viewed as a challenge to be managed. Clergy, counselors, friends and support groups can help you discover or create such meaning. Inspirational books, such as Kushner's *When Bad Things Happen To Good People,* can also be useful. Finding the "right" or "perfect" answer to your question may not be as important as your comfort in thinking about things differently.

STAY IN TOUCH

- Join a support group of persons who are in similar caregiving roles. It is an opportunity to share feelings, reduce isolation, exchange ideas for coping, and identify other community resources. Some support groups are for caregivers of older adults, while others are very specialized (e.g., Parkinson's and Alzheimer's support groups, stroke clubs, etc.).
- Join an organization in the community that assists disabled persons and their caregivers, such as the Alzheimer's Disease and Related Disorders Association (ADRDA), the American Association of Retired Persons (AARP), Senior Coalition or Senior Center. These groups provide a variety of ways to share feelings, support legislation and research, provide information and advocacy. They may also be able to direct you to sympathetic health care professionals.
- Get together with friends or join a club to pursue hobbies, crafts, or just a "coffee klatsch."
- Go out to dinner, a movie, play, craft fair, museum, or shopping.
- Take time to stay in touch with people through letter writing and phone calls.
- Volunteer to help at some activity (e.g., a wedding, bake sale, repairing toys). It is still a "helping" role, but it is with others and involves different efforts.
- Take a community education, vocational, or college course. Most programs have reduced rates for senior citizens.

Hold family meetings. Not only are meetings of all family members an opportunity to socialize and show your love and concern, but they can provide the chance for family members' involvement in the care planning and decision making. When people have input on decisions, they usually feel greater commitment to carry out the plans, as well as being less critical of you.

Journaling. Keeping a daily journal, day book or diary is another way to reflect on and make meaning of the caregiving relationship. In the midst of stress it can be difficult to think clearly of alternatives. The journal allows you to note problems, ideas, and successes and to reflect on them when you are thinking more clearly. The end of each day is often selected as a time for writing new entries and reading old ones. It also becomes a document for reviewing your own coping progress. Tailor it to your own needs: add poems, quotes, anecdotes, and drawings that express your feelings or the day's events.



Summary

Just because you use several of these techniques for managing stress does not mean that your stress will be completely under control. If these activities were that easy to do, you would have probably done them already. They require commitment to carry out. However, their regular use will enable you to view stressful events in a healthier way. The stages of stress described in the chapter can be used as an "early warning system" to alert you to problems that may be arising from caregiving. "Taking care of yourself" is one of the best things you can do for the person you are caring for!

Chapter 4

Communication in the Family

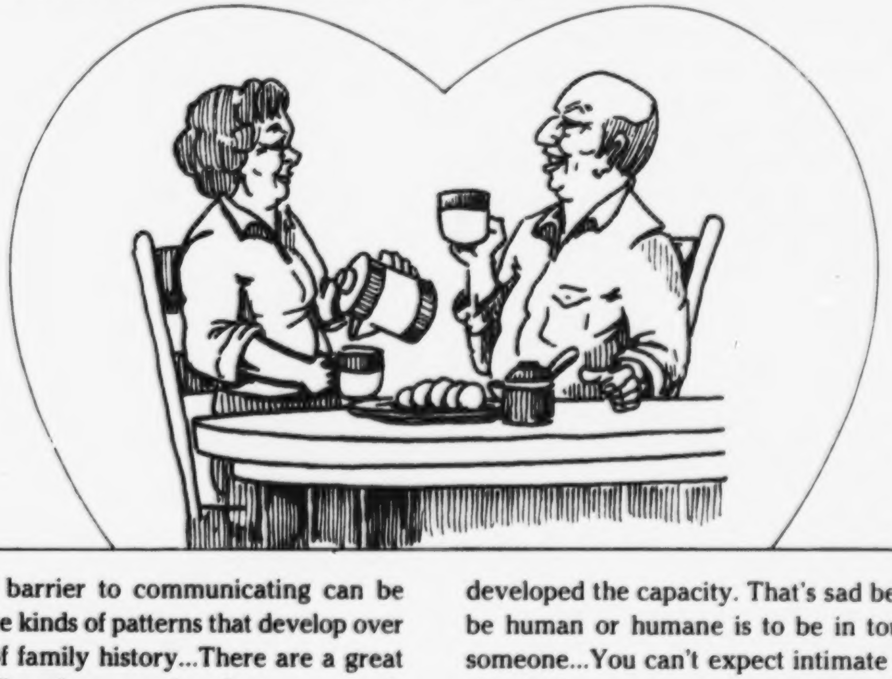
Dan Johnson
College of St. Scholastica

Why Is Communication Important?

If you are caring for someone who matters very much in your life, you know how important the relationship between the two of you is. Without the support that we get from relationships, or without other human beings with whom we can share our deepest joys and fears, the will to live can be lost. Relationships are that important!

You probably are aware, however, that the caregiving situation has frustrations that can strain these important relationships. When stress is high, we often fail to accurately communicate our intentions; instead, we communicate fleeting emotions. For example: a harsh word might slip out, or the voice might communicate irritation, or the face might look disgusted. We may end up hurting the person we truly care about.

Without communication, relationships cannot thrive. Because of the concern and love you feel for the person you are caring for, it is important to maintain good communication so that your relationship does thrive. This chapter will help you do this by discussing how communication can create more effective and satisfying relationships. "Knowledge is power," and knowledge about communication can be a very powerful way to reduce strains in relationships.



> The main barrier to communicating can be found in the kinds of patterns that develop over 50 years of family history...There are a great many families whose members have never really talked, never understood communication or developed the capacity. That's sad because to be human or humane is to be in touch with someone...You can't expect intimate relationships when you haven't cultivated them.
>
> J.A. Peterson quoted by M. Briley in *How to Close the Gap with Your Parents.*

What Does Communication Really Mean?

Here are some words that are like shoots of a plant that share the same root: commitment, committee, communal, communion, community, and companion. And, our word in this chapter, **communication**. The common root ("com") is from the Latin word meaning "with." Are you "with" me? If you are, and I am "with" you, we are together. We make a team together—professionally, as neighbors or volunteers, as mates, nephew and aunt, friends. Each of us needs to be "with" another human being at some level at any one point in our lives. It started when we were born, and it is no less urgent when we reach old age.

We are "with" each other through communication. Yes, through the words that we say to each other, but even more important than words, we communicate with our eyes, facial expressions, gestures, touching, and tone of voice. Or, sharing silence together—just being with each other, in each other's presence. These are aspects of nonverbal communication, and they convey much of the meaning exchanged in a conversation between two people!

A psychiatrist friend in Los Angeles told me once of the following experience. Late one night he was at the Los Angeles General Hospital and had occasion to go to the surgical waiting room. There was only one person there, a woman who was sobbing as though her heart would break. He asked the nurse on duty who it was. She said, "That is Mrs. Gonzales; her husband has just died on the operating table." He said, "Oh, I know the case." He went over and sat down by her, and said, "Mrs. Gonzales, I am Dr. Ingham. It happens I knew about your husband's case. He had the best of care; I know the surgeon..." and he went on. As he talked, her crying subsided, and was replaced by a few whimpers; then she quieted down and was even able to smile a little through her tears, as she held his hand. He sat and talked with her for some time, then looked at his watch and realized he had to leave. As he was walking out the nurse on duty called him over and said, "Dr. Ingham, I didn't know that you spoke Spanish." "Spanish! I don't know any Spanish." She said, "Well, then, what were you talking about with Mrs. Gonzales? She doesn't know a word of English." That really was talk, real communication.

A. Kaplan, "The Life of Dialogue," *Communication: A Discussion at the Nobel Conference (1971).*

Through my relationship with you, I learn who I am. As I talk with you, and you respond to me, I suddenly understand things about myself I never knew. In good relationships each partner grows. Because we are together we are different people than we would have been had we remained alone. Because we've been together, I have become so much more than I was before we talked together. And our relationship is likely to remain strong as long as being together increases self-esteem, self-awareness, and personal continuity. I may be bedridden, hard of hearing, and scared and angry at times, but I am still trying to figure out who I am and what I shall become. Without you to be there with me, I worry about being able to make it myself.

The Importance of Reminiscence in Communication

Does aging affect the content of what is communicated? It sure does! Do we talk about the same things as a teenager that we talked about as a four-year-old? In the middle of our lives as we did as young lovers? We shouldn't be surprised that an older person needs to talk about different things than she did as a young parent. The difference between the things older people need to talk about now as compared to earlier stages in their lives is called the **life review** or **reminiscence**.

Frequent and repeated references to past events tend to annoy some younger people. But rather than shutting it off, sighing, or allowing ourselves to appear bored, those of us who haven't reached the stage of needing to reminisce should encourage it and take our loved one further in discovering the meaning of their life experiences. It is the stuff of our family, our tribe, our clan! Through our loved one's reminiscing, we have a chance to learn more about ourselves. Reminiscing gives us a wonderful chance to interview and record these stories for future generations.

You can take the initiative in conversations by asking questions to give the person clues as to what you would like to hear about regarding her life. By doing this you are not only benefiting the older person, but you will also find that your own life will be enriched by her life experiences, her special perspective on life, and by finding out things about her (and about an earlier era) that are extremely interesting. Listed in the following box are several other ways in which you can participate in the life review.

PARTICIPATING IN THE LIFE REVIEW

- Ask for a written or tape-recorded autobiography.
- Go with the person on a "pilgrimage" to places that were important in her past.
- Arrange reunions.
- Ask for help in writing a family genealogy.
- Look through scrapbooks, photo albums, old letters, and other memorabilia with the individual.

Why is reminiscing so important for older people? For some, it is a way to order one's life before death, to "connect the dots" of one's life so its pattern and meaning can be seen more clearly. It is through our reminiscing that we share our past and explore our future. But reminiscing also is a type of communication that contributes to self-awareness, self-acceptance, and a sense of personal continuity. Isn't that something! That's how we started life and how we live our lives—seeking fulfillment of these three needs: self-awareness, self-acceptance, and a sense of personal continuity. Everything changes, and yet everything remains the same.

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How Can Aging Affect Our Ability to Communicate?

Changes that take place in vision and hearing as we age may interfere with our ability to communicate. The most dramatic changes occur between the ages of 50 and 70:

- Loss of flexibility in the lens of the eye leads to the need for bifocals in many middle-aged people.
- Yellowing of the lens distorts color vision and greatly increases the amount of light needed to see well.
- Some people develop cataracts which blur vision.
- Loss of sensitivity to higher pitches of sound requires that we try not to speak to older people in high pitches and that we avoid distracting background noises such as radios and fans when conversing. Shouting, incidentally, only raises the pitch of our speech and distorts sounds even more.
- Stroke, Parkinson's disease, and other diseases which affect muscles can affect speech. Most of us have talked our way through life unaware that more than 100 muscles are involved in speaking a simple sentence.

As hearing and sight losses increase, reduced information about the world may give us the feeling of a shrinking world. We become more isolated, lose self-esteem, and may even become confused. Sometimes as losses increase, the recognition becomes so frightening that an older person cannot accept it and, therefore, blames his losses on others. "Don't mumble!" "How can you stand to sit around in the dark!" "Speak up!" We can hear the frustration in those voices. Other older people say nothing, and nod and smile even when to nod and smile doesn't make sense. In either case, loss of hearing and sight diminishes contact with the world. As the losses increase, often so does withdrawal and self-imposed isolation. Even though we may know better, it is hard to accept undeserved blame and to be on the receiving end of a frustrated person at any age. "I don't need this," we say to ourselves in response, and so we come less frequently to visit the older person. When we do visit, we spend less time and our time together becomes less meaningful. As communication is reduced, so is the relationship.

Because a person sees and hears less well, what does she do when you come to visit or to care for her? She tends to move closer to you, to reduce the space between you so that she can see and hear you better. But even this behavior gets the older person in trouble. Why? Because very powerful, but unspoken, social rules govern how close we are "allowed" to get to each other. If someone gets closer to us than we are accustomed, we become nervous. We may feel uncomfortable because our space has been invaded, and so we pull back physically from the older person and may even spend less time together.

To heap insult on injury, many of us tend to use the same tone of voice as we do with babies when we talk with older persons we perceive as less competent. We may not realize it, but the older person does. So we unintentionally reduce the communication between us, and the quality of the relationship is diminished.

A relationship requires give-and-take of both persons. Relationships are two-way interactions. But the relationship tends to become more one-way as the persons we care for become less able to nurture us in return. As caregivers, our greatest challenge may well be to help our loved ones accept a declining role in our relationship, celebrate past successes, and assure again and again that the affection and love built up in the past is more than enough to sustain and further enrich our remaining time together.

Listening

Listening skills are just as important as talking skills in our relationship with the care receiver. Many of us aren't as good as we could be in listening actively to what others tell us or in tailoring what we say (verbally and nonverbally) to others.

Why? Because we forget that we have to decide to listen. To listen actively requires that we give the other person our full attention. We have to stop doing what we're doing. If we cannot stop putting away the groceries, cooking, listening to music or watching TV, or if we are too tired, then we must withdraw and say, "I'm sorry, but I can't right now because...but let's talk after supper."

When we are really listening, others know it. They also know when we are not and just pretending. How? Because when we have decided to listen actively, there is a tendency to lean forward. We look directly at the other person and not at a paper, book, pencil, or clock. We let our faces reveal appropriate caring and reassuring emotions. We may touch the person's shoulder or arm, or hold her hand. And, we may vocalize our support with "um-hmmm's." I cannot do all these things, or some of them, if I am thinking about something else. I can do them only if I have decided to give you and what you are saying my full attention.

Active listening may also include responding with words, too. But studies of verbal listening responses reveal that most frequently we use judging words, words as useless as the parental, "Drive carefully!" Or, "If I were you, I would..." Instead, it might be helpful to respond with:

- reassurance: "I can understand why you..."
- a question: "Does that mean that you...?"
- paraphrasing; putting into your own words what you heard the person say: "If I understand what you mean, you're saying that..."

It is remarkable how questioning and paraphrasing can help one understand the other person better and even help the other person understand himself or herself better. Communication depends on listening.

Words: It's Not What We Say, But What We Mean

You often hear people talk about "communication failure," but it isn't really an accurate statement because we never fail to communicate. We may not end up communicating what we intended or we may not have our meaning accurately understood, but we always communicate. In fact, it is said that "we cannot not communicate."

Just because I said what I meant does not mean that you understand what I mean. Meaning is in people, not only in words. For example, the word "mother" means positive things to someone whose mother was loving and nurturing, but conflicting and negative meanings for someone whose mother was abusive.

MOM'S
HOME
COOKING
THE
FROSTING
BOWL

The meaning we give to words often depends on our experience with them and on what we are feeling at the present time. The 500 words we use most frequently have a total of 14,000 different meanings. Add to that the different experiences people have with what the words refer to, and it's a wonder we manage at all! As Joseph DeVito puts it, "Failure to understand another person or to be understood are not abnormal situations; they are inevitable and should make us realize that we can always understand each other a little bit better than we do now."

Ask yourself this question the next time your loved one reminisces: "I wonder what it really means—that same story I've heard a million times. I wonder what it means to the one I care for. I wonder what it could mean to me."

Words get additional meaning from facial expressions, gestures, and body posture. I may not be saying a word, but my posture, face, eyes, and sighs say everything about the mood I'm in. One study shows that if I'm unsure of what you really meant when you said, "I love you," I will tend to put more credibility in your tone of voice and facial expression than in your words. Words, indeed, can be cheap. It's not just what we say that matters. By leaning forward, smiling, and maintaining eye contact, your body language can encourage the other person to speak.

Summary

Communication is the cement with which relationships are initiated and maintained throughout our lives. Because older persons may have physical limitations that restrict their interactions with the world, it is crucial to maintain relationships with them by using what we have suggested in this chapter. Additional techniques which would be helpful to you and to the care receiver are presented in the next chapter.

Chapter 5

Techniques For Aiding Communication

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What this Chapter Offers

In Chapter 4 on *Communication in the Family,* we discussed communication in terms of its social benefits and its impact on relationships. Our focus in this chapter will be on various types of physical conditions which can affect the ability of older persons to communicate with family members and friends.

Because communication is affected differently by specific disorders, we will present examples to illustrate how each condition requires different ways of enhancing older adults' ability to talk to others and to understand what is being said to them. Throughout the chapter, practical suggestions are offered for facilitating communication, and information is provided about devices that are available to help older persons communicate. In order to get the most out of this chapter, search for the information which is applicable to your situation and to your needs as a caregiver.

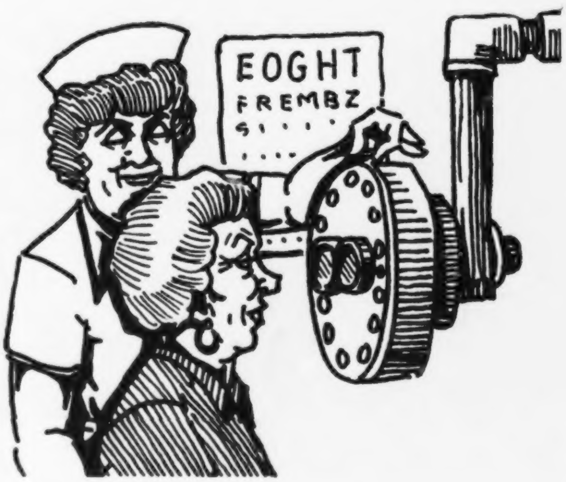
Vision Loss

The most dramatic changes in vision occur between 50 and 70 years of age. By the time an individual reaches the age of 85, he needs much more light to see properly than he did when he was younger. The following example suggests difficulties that may result from poor vision.

> **Sarah, 76, and Simon, 84 years old, live in their own home. They have weekly visits from a worker from the county chore service program and are periodically visited by the public health nurse. Lately, Sarah has not been writing checks for bills, has fallen a few times, and is reluctant to leave the house to go shopping. She has also not been willing to read stories to their grandchildren when they visit.**

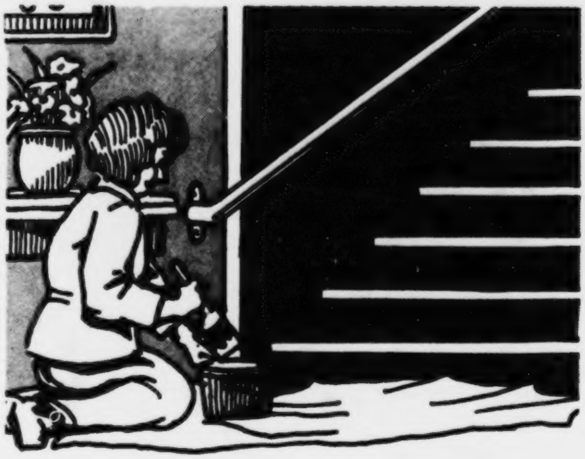
Sarah could be displaying signs of a number of disorders; however, for our purposes we will say she is experiencing visual loss. As with any change in physical function, the first step is to have a medical evaluation. There are numerous causes for visual impairment, none of which should be taken lightly.

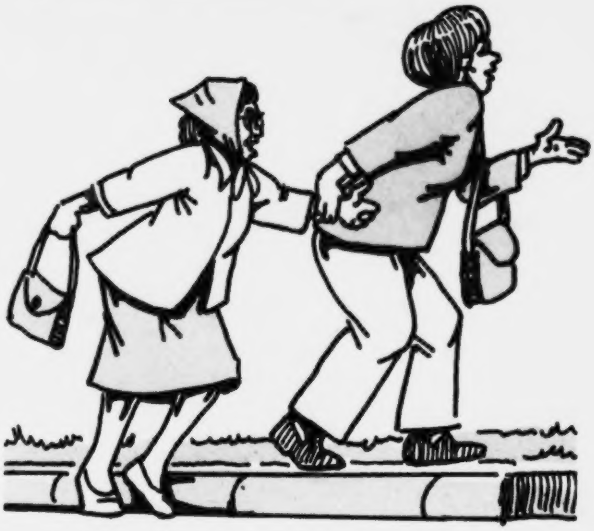
It is important to realize, as shown in the first box, that there are many ways in which persons with visual difficulties can be assisted.



ASSISTING PERSONS WITH VISION LOSS

- Provide large print books. Some magazines, such as *Readers Digest* are also published in large print. For less serious visual impairment, hand-held magnifying lenses can be useful.
- Provide "talking books" or audio tapes.
- Use clocks with white numbers and black background.
- Large number telephone dials are available.
- Clearly label rooms, objects, etc.
- Rearrange furniture so that sunlight can be provided for illumination.
- Avoid light glare.
- Accent dangerous edges, such as on stair steps and head-level obstructions, with strongly contrasting colors.
- Do not rush visually impaired individuals as they walk.





Communication can be affected by vision loss. In the next box we have listed some practical suggestions for communicating with a visually impaired person.

COMMUNICATING WITH THE VISUALLY IMPAIRED PERSON

- Always include visually impaired individuals in the conversation, and don't "talk down" to them.
- People often have a tendency to raise their voices or even shout to visually impaired people. There is no need to do this.
- Ask visitors to identify themselves to the visually impaired person before beginning a conversation.
- Alert a visually impaired person verbally before touching him.
- Lightly touching the person's shoulder or hand may be useful in aiding her in determining your position.
- Be willing to help if needed, but don't assume that the visually impaired person is unable to do things without your assistance.

Hearing Loss

Let us next look at the situation of a person with impaired hearing.

- **Joe, 72 years old, is a retired steel worker and is enjoying his retirement except for his constant need to ask his wife and friends to repeat what they have said. He sometimes will not ask what was said and simply nod his head in agreement. It also puzzles him that he can understand some people and not others. He continues to wonder what is wrong but blames it on old age.**

Joe appears to be experiencing a significant hearing loss, and he attributes to "just getting older," with the attitude that nothing can be done about it. You might be interested in the following basic facts that Joe needs to know. With this knowledge, you can help the older person with a hearing loss explore the best possible alternatives and assist him in obtaining qualified professional help.

- All suspicions of hearing loss should be evaluated by a physician specializing in hearing, preferably an ear, nose, and throat doctor.
- Some hearing losses can be corrected or partially improved through the use of medications or surgical intervention.
- The older person's hearing should be tested by an audiologist who has certification through the American Speech-Language-Hearing Association (ASHA).
- Hearing aids can help some people with a loss, but hearing aids will not do much good for some older persons. Unlike the normal vision that most people who wear eyeglasses have, many people with hearing aids do not have normal hearing.
- All hearing aids should be purchased on a thirty-day trial basis. Sometimes the wearer cannot tolerate the aid. The trial basis will allow you to return the aid for a full refund.

AUDIOLOGIST
HEARING AIDS

Additional devices are available for hearing impaired persons who are unable to benefit from hearing aids. These other types of listening devices can be obtained at many of the retail outlets that sell hearing aids. For example, there is an amplifier that can be placed in the receiver of your telephone to make the caller's voice louder. Other devices allow the television to be amplified for the hearing impaired person while maintaining a normal volume for the rest of the family. These are just two examples of the types of aids a hearing impaired person can use to maintain communication with family and friends.

COMMUNICATING WITH THE HEARING IMPAIRED PERSON

- Speak at your normal rate of speech but not too rapidly. If you are known as a fast talker, slow down. However, do not over-enunciate.
- Talk as you normally would with a slight increase in loudness of your speech. **Do not shout.**
- Three to six feet should be between you and the hearing impaired person. Conversation will be improved when people are in closer proximity.
- Be sure your face is visible to the listener. Be sure there is light on your face.
- Do not speak directly into a hearing impaired person's ear. The hearing impaired person looses the opportunity to watch the speaker's face.
- Talk in a quiet setting. Shut off the TV or radio or move yourselves to a quiet room.
- If your message is not understood, rephrase the message using different words.
- Treat people with hearing losses as adults and always include them in the discussion.
- Consider learning sign language.

Strokes

Strokes result from disruption of the blood supply to the brain, which can happen when there is a blood clot (thrombosis) or a when a blood vessel bursts (aneurysm). The resulting temporary and/or permanent damage to a part of the brain is what causes symptoms like paralysis, speech problems, vision problems, etc. Let us look at the case of a woman who suffered a stroke.

- **Martha, 69 years old, is a retired librarian and suffered a stroke a year ago. She is presently living with a family member but hopes to move back to her apartment soon. She went through physical, occupational, and speech therapy. Now she is able to get around with minimal assistance, but she still cannot say what she is thinking. The words just won't come. She really misses being able to talk with her family members and her other friends who come to visit.**

Though Martha is having difficulty speaking due to a stroke, we wish to caution that all people who have had a stroke do not have the same types of disabilities. The type of disability depends entirely on the place in the brain where the stroke happened and the amount of the brain which has been affected by the stroke. The next box lists some ways you can make communication with the stroke victim more satisfying.

COMMUNICATING WITH THE STROKE VICTIM

- Communicate in a quiet place free of competing noise.
- Be sure you have the person's attention before giving him instructions, and keep instructions or questions short, simple, and direct.
- Use facial expressions to help communicate your message.
- Do not overreact or be surprised to hear swearing. Remember, the stroke person has difficulty choosing her words and monitoring what she says.
- Encourage all attempts at speaking. Be patient, listen, and attempt to figure out what he is trying to say.
- Be sure all written material presented to the stroke victim can be seen. Some people cannot see to the left or right side of material.
- Be sure not to talk down to the person. Treat the person as an adult.
- Just because a person cannot talk does not mean that she cannot understand.
- Do not talk about him in his presence.
- Do not assume the person understands everything. Ask her if she understands.
- Some people need extra time to understand information and also extra time to put their thoughts together to respond to the information. Give the person enough time to understand and to speak.
- Do not correct errors. Instead, repeat what you think the person was trying to say.
- Just because a person said a word one day does not mean that he is able to say it any time he wants.
- Give the person hints on how to say the word if you know what she wants to say.
- If the person has little or no intelligible speech, ask questions requiring a yes/no response. response.
- Be supportive and understanding without indulging in unrealistic optimism.

If you need more information on how to help the stroke victim communicate, contact a local "speech-language pathologist." He/she will be glad to assist you. If you live in a rural area and do not have access to a speech-language pathologist, we suggest calling the American-Speech-Language-Hearing Association at 1-800-638-6868. They will provide you with names and phone numbers of persons in your region who can help you.

An Augmentative Communication System for Stroke Victims

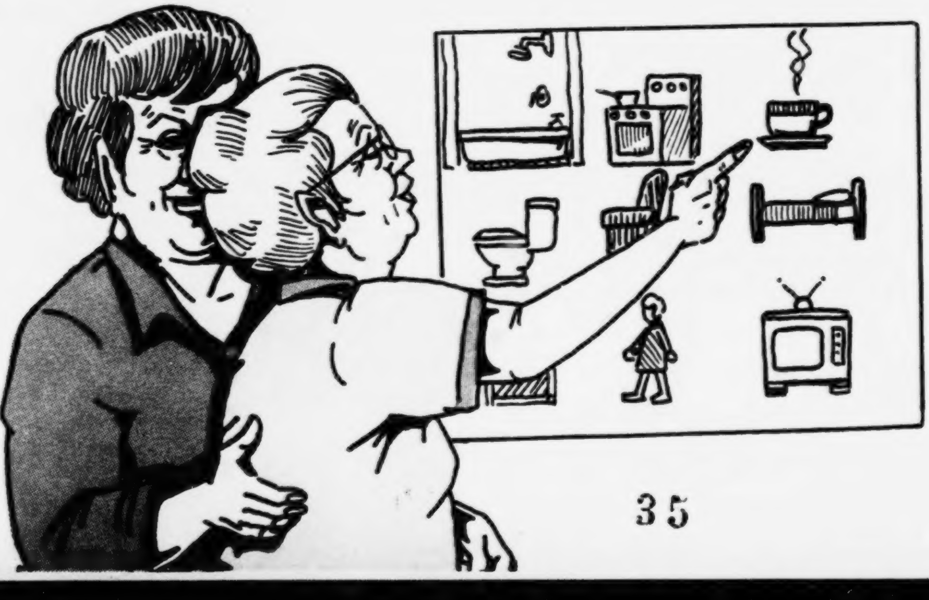
The term "augmentative" simply means an alternative way to communicate when you are unable to speak. We will refer to "augmentative communication systems" as ACS. An ACS can range from very simple setups up to the latest technology in computers and synthetic speech. Here are some examples of ACS's:

- A heavy piece of cardboard with the letters of the alphabet written very large. This allows the person to spell the words if he is unable to say them, assuming that the patient's ability to spell remains intact.
- A heavy piece of white cardboard that contains pictures of items in the person's house, such as the bed, chair, bathroom, kitchen, and bath. This allows the person to indicate what she wants or where she wants to go by pointing to the most appropriate picture. This type of ACS is also known as a "communication board." These can be made as elaborate as the person is able to use, including written phrases such as "I want" plus words or pictures the person can point to.
- The more elaborate types of systems available consist of phrases printed on a computer board. The board or machine will then speak the phrase or sentence that the person has pushed. The variety of such machines is great. If a person cannot read, pictures can be used and the machine can be programmed to speak the word when the person pushes the picture. The cost of these machines ranges from $150 to $4,000.

There are some basic points to keep in mind when considering an ACS for a stroke victim:

- The stroke victim should have an evaluation by a speech-language pathologist to determine if she could benefit from such a system.
- Not all stroke victims will be able to use an ACS.
- Not all stroke victims will want to use an ACS. These individuals want to try to communicate without it.
- All hardware (the computer, the synthetic speech machine) should be tried with the individual prior to purchase.
- Check out the warranty period and availability of maintenance service when purchasing costly augmentative devices.

In summary, all stroke victims are not the same. Each has his or her own abilities and disabilities. They are adults who must be treated as individuals. Every effort should be put forth to assure that they continue to communicate to the best of their ability, and all attempts should be made to keep stroke victims as active members of their society.



Neurological Dysfunction

Let us begin our discussion of neurological dysfunction with an example of a person with Parkinson's disease.

- **Pete, a 75-year-old, has been diagnosed with Parkinson's Disease. He is presently on medications that help control the disease. Recently, he has noticed that his speech is softer, that he is unable to say his words without slurring them, and it is difficult for him to eat as rapidly as the rest of the family. He has noticed that friends talk to him less, and they "talk around" him instead.**

Pete's case illustrates the difficulties experienced by older persons who suffer from neurological disease. Parkinsonism, multiple sclerosis, Alzheimer's and amyotrophic lateral sclerosis are the major diseases you will hear about or encounter. As with stroke victims, the person who suffers from a neurological deficit needs specific techniques to help her communicate. The list in the next box will give you some guidelines to follow for working with persons who have Parkinson's disease. If the older adult has one of the other neurological deficits mentioned above, specific recommendations and suggestions can be provided by her physician, a speech-language pathologist, and/or a support group in the community or region.

COMMUNICATING WITH A PERSON WHO HAS PARKINSONISM

- Encourage the person to speak slower, one word at a time if necessary.
- If the speech is too fast, have the person pace his rate of speech by tapping on a table with his hand for every word he says.
- Encourage the person to open her mouth and say the words as clearly as possible.
- Encourage the person to speak louder.
- Don't expect the person to be able to maintain the appropriate level of loudness or slowness. She may be able to do it only for a short period of time and then must rest and be encouraged to try again.
- If the loudness of the speech is difficult to maintain, consider purchasing an amplifying system. These can be purchased at Radio Shack for under $40.

Here is another example of a person with a neurological dysfunction, this time one that affects memory.

- **Lena, a 92-year-old, has been active with her friends and has been living alone for all these years. She has traveled between her homes in Minnesota and Texas for 40 years and has enjoyed her lifestyle. Recently, Lena has noticed that she forgets things. She forgets names, appointments and even whether or not she has eaten a meal. She admits her memory is not as good as it used to be, but after all she is 92 years old and what can you expect.**

The main problem in Lena's case is a decrease in intellectual abilities, such as memory. Other intellectual deficits, such as ineffective problem solving, may also occur that will require special treatment in order for a person like Lena to remain active and as independent as possible. For additional information, turn to the memory and dementia sections in Chapter 9 on *Psychology of Aging* and to the memory impairment section in Chapter 7 on *Nutritional Needs.* Some suggestions for helping a person with reduced intellectual ability are listed in the next box.

COMMUNICATING WITH THE INTELLECTUALLY IMPAIRED PERSON

- Touch the person when talking to her.
- Speak in simple, short sentences.
- Use meaningful inflections, and combine speech with meaningful gestures.
- Do not expect the person to remember several facts.
- Do not expect the person to hear everything you say.
- Be honest with the older person concerning your own limitations and strengths. (See Chapters 2 and 3 for more discussion of this topic.)
- Listen to what the older person has to say both verbally and non- verbally. (See Chapter 4 for more discussion.)
- If memory is a problem, consider making daily schedules with appointments and "must do" items.
- Allow the older person to participate in decision making concerning himself. Give him the time, a few days if necessary, to come to a decision while you continue to provide factual information.

If you are the caregiver of a person with neurological deficits, we encourage you to seek professional help from the resources in your community, such as are listed earlier in this chapter, in Chapter 9 on *Psychology of Aging*, and in Chapter 12 on *Where to Get Help*.

Summary

We would like to emphasize that each person remains an individual, no matter what the age is. Each person uses communication to socialize and interact within his or her everyday environment. It is essential that you as a caregiver use all possible techniques to ensure that communication is kept at the highest possible level. The suggestions in this chapter can be of great help to you in achieving this goal. It is also necessary to be aware of and to work within your limitations. Recognizing the limitations of the older person is also essential for maintaining realistic expectations.

Chapter 6

Changes in the Body

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What Is Aging?

This chapter provides an overview of the normal changes in the body that can be expected to occur during the human aging process. Recent advances in medical research have vastly improved our knowledge about aging, and we are now better able to distinguish between changes that result from normal aging and changes due to disease.

Gradual decline. Aging can be defined as "change with time." This suggests that human aging begins at the time of conception and then moves through a series of stages until eventual old age. Although we usually notice outward signs of aging (such as graying hair), we are usually unaware of the slowly occurring changes *within* our bodies. Indeed, this physical decline is so gradual that it is difficult to measure in less than a five-year period and nearly impossible to define exactly when a specific decline begins. In fact, different body organs and systems age at different rates, and, not counting disease and accidents, functional loss in most systems is no greater between the ages of 50 and 60 than it is between the ages of 30 and 40!

Individual differences. The rate of physical decline varies a great deal between individuals. At any one age, for any one function, different individuals might have losses ranging from 5% to 50%. This illustrates that different people age at different rates. The important point is that a person's **biological age** is usually quite different from his or her **chronological age** (the number of years since birth). Thus, biological age is much more useful than chronological age for assessing fitness and aging rate.

Homeostasis. "Homeostasis" is defined as the state of balance (or equilibrium) in body fluids and tissues. As changes in body function occur, there is a general decrease in the body's ability to maintain balance within various systems. Many homeostatic systems (such as blood pH, blood sugar level, body temperature, and pulse rate) change very little with age as long as the body is at rest. But, if the older body is stressed, either physically or emotionally, there is a decreased ability to respond to this stress and maintain a balance. For example, the older person's body temperature changes more than a younger person's as the temperature of the surroundings changes. It also takes longer to return to normal temperature.

ARE WE LIVING LONGER?

Life expectancy is that length of time that an individual is likely to live from the moment of birth. A child born today can expect to live to about age 75, a whole 28 years longer than a child born back in 1900. This life expectancy is not to be confused with **maximum life span**, which is the age to which the oldest members of our population survive. For humans, maximum life span is believed to be genetically fixed at about 115 years. Because of the increased life expectancy, people often say that the maximum life span of humans is now much longer than ever, but this is not true. Although some of the increase in average life expectancy is due to the improved health and medical care of older people, most of the increase is actually due to decreased mortality rates in infants and children. It also looks as if the maximum life span is increasing because every year the number of elderly people increases. So, in answer to the question, "Are we living longer?", we can say that more and more of us are surviving into old age but that the "cap" on our maximum life span has not changed very much.

In the following sections we'll discuss normal changes in the aging body.

Skin and Hair

The skin is one body system that is often overlooked when talking of physiology, but rarely missed when thinking of aging. Age changes in skin and hair are usually the first-noticed and most often-used indicators of your chronological age. Older adults' skin generally shows increased paleness, wrinkling, loss of elasticity, dryness, and pigmentation spots.

Why does skin become more **wrinkled** with aging? Alterations in tissue (called collagen and elastin) below the skin account for most of these changes. Notice how when skin on the forehand of an older person is pinched, the wrinkle stays up briefly rather than snapping right back down as in a young person. Also, there is a loss of the fat below the surface of the skin and a weakening of tiny blood vessels which can result in small black and blue spots. There is little doubt that exposure to ultraviolet radiation from sunlight accelerates the rate of aging in skin.

Although some **baldness** is genetic and related to male hormones, loss of scalp hair and graying of hair are common occurrences in middle and late life.

Muscles

The muscular system shows age changes mainly by a decrease in size and strength. Skeletal muscle cells decrease both in number and size with age. Muscle mass generally decreases after the age of 50 with much of the muscle tissue being replaced by fat and connective tissue. Muscle strength usually peaks between the age of 20 and 30 and then slowly declines. Some decline in muscle size and function is undoubtedly a consequence of disuse, but this cannot be the whole answer since muscles of the hand, eye, and larynx (voice-box) also show age changes. Whatever the cause, physical activities within one's limits are certainly recommended for maintaining muscle health and slowing muscle aging.

Skeletal Changes

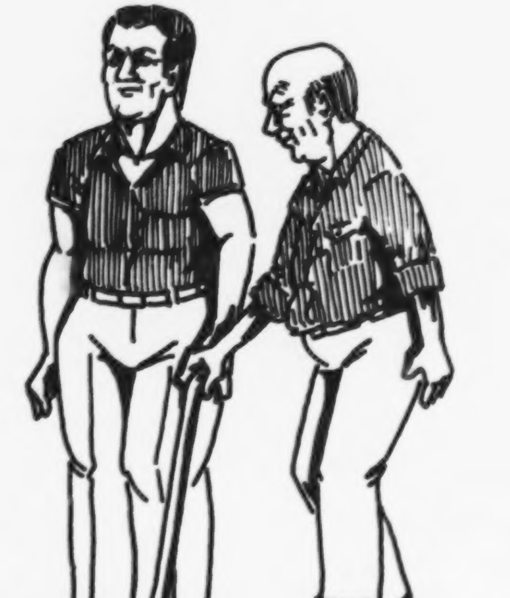
Why do we get shorter and stiffer? The reduction in height and the limited mobility that comes with aging is primarily a result of skeletal changes. Decreased density of bones and deterioration of ligaments, cartilage, and joints contribute to changes in body height and narrowing of chest and shoulders. There may even be some thinning (collagen loss) or collapse of spinal discs to add to height loss. The changes in ligaments and cartilage lead to the characteristic stiffened joints of the aged.

Osteoporosis, the accelerated thinning of bone seen particularly in post-menopausal women, is primarily a result of bone mineral loss. The cause for this loss is not known, although diet (low calcium intake) and hormone levels (drop in estrogen following menopause) are suspected as contributing factors. Recently there is evidence that planned physical activity programs can slow down the rate of adult bone loss or even restore bone in older individuals.

Heart and Lung Changes

The heart and blood vessels. Aging of the circulatory system often leads to cardiovascular (heart and blood vessel) disease, which is at present the number one health problem in the United States. More people die from heart attacks and strokes than from all other causes of death combined. There is no doubt that the occurrence of cardiovascular diseases—such as arteriosclerosis and atherosclerosis (see explanations two paragraphs below), heart degeneration, cerebral hemorrhage (stroke), coronary thrombosis (blockage of blood to the heart due to a clot), and hypertension (high blood pressure)—increases with age.

Gradual changes in the heart and blood vessels can be seen even before cardiovascular diseases become obvious, and they can result in decreased blood supply to the body organs. Such changes include (a) a decrease in the heart's reserve capacity, (b) poor reaction by the heart to sudden stress, (c) heart output drops about 1% per year below the normal for young adults, (d) there is a thickening of the valves and inner lining of the heart, (e) and the blood vessels progressively become more stiff and less elastic.



Some of the changes occurring in blood vessels that are often attributed to disease may in fact be part of a normal aging process. For example, **arteriosclerosis** is a general term which refers to a thickening and hardening of the arterial walls. Atherosclerosis is a specific kind of arteriosclerosis characterized by fatty accumulation in the innermost layers of the arterial wall. These fatty accumulations, along with the connective tissue changes, form white, scar-like areas called atheromas or plaques. Such damage to vessel walls can eventually lead to vessel obstruction, formation of internal blood clots (thrombus) or rupture of vessel walls (aneurysm). This then becomes the heart attack or stroke referred to earlier.

The lungs. The respiratory system has one main function, which is to exchange oxygen and carbon dioxide between blood and the breathed air. Although with age there is little change in total lung capacity, there is a decrease in the total amount of air that can be moved in and out of the lungs (vital capacity) and an increase in air still left in the lungs (residual volume) after maximum effort to exhale. Obesity and changes within the bones, muscles, and connective tissue of the chest wall, including the diaphragm, are largely responsible for these volume changes. As expected, there is also decreased lung elasticity associated with age.

SMOKING

Smoking is a prime example of how environmental damage can accelerate aging. There is no question that smoking is the single most preventable cause of disease and premature death in the United States. Not only does it dramatically increase the risk of cancer, emphysema and bronchitis in the lungs, but it also increases the risk of cardiovascular disease and ulcers in the digestive system.

Digestive Changes

Should diet change as we grow older? The digestive system, particularly the digestive tract, does not show as many age changes as do many other systems. Most digestive problems of elderly people are more of a nutritional than physiological nature. Too many Americans consume excess fat, salt, and sugar in their diets. Others, particularly the very old, are often undernourished with not enough vitamins and minerals. Most people experience teeth problems as they grow older (more gum than decay problems), and along with the decline in sense of smell and taste, dietary patterns are often altered. See Chapter 7 on *Nutritional Needs* for more information on diet.

Age changes in the digestive tract show up as decreased acid secretion in the stomach, decreased movement in the stomach and intestines, and possible decreased calcium absorption. The acid in the stomach can interfere with specific enzyme activity and thereby protein digestion. It is also possible that age changes in the stomach lining may be responsible for decreased Vitamin B12 absorption which can lead to anemia. The decreased motility or peristalsis of the digestive tract simply means that digestion and absorption usually take longer, but this can also mean that constipation might result.

Another part of the digestive system, the liver, has received considerable attention with regard to age studies, and has been shown to function fairly well into old age. There is a slight drop in blood flow through the aged liver and there are some cell changes, but the tremendous reserve and regenerative capacity of a non-diseased liver keeps it in good working order.

Urinary Changes

The kidneys, the central part of the excretory system, are the key organs in clearing blood of wastes, maintaining water and electrolyte balance, and controlling acid-base balance.

Why is frequent urination a common problem in older adults? In men this is usually caused by enlargement of the prostate, while in women infection of the urethra and bladder is often responsible. Sometimes it is caused by medications taken for other conditions.

Incontinence, which is the inability to control bladder or bowel function, is a concern for many older adults. It is estimated that one in ten persons over age sixty-five experience bladder control problems. Women are more commonly affected than men. It is important for caregivers to know that incontinence often can be treated and controlled.

If incontinence is a problem for the person you are caring for, the first step is to seek medical evaluation for the older adult. Three common types of urinary incontinence are stress incontinence, urge incontinence, and overflow incontinence. Each may have a different cause or treatment. In the box below are practical suggestions in dealing with incontinence.

DEALING WITH INCONTINENCE

- Be sensitive to the needs of the older adult, both psychologically and physically.
- Behavior modification has been an effective treatment in some cases. Ask your doctor for a referral to someone who can teach you some of the techniques.
- Establish a regular routine for bladder and bowel elimination.
- If needed, purchase large supplies of disposable pads at a hospital supply store, or check with your public health nurse about where to purchase such items.
- Install a portable toilet near the bedside at night.
- Include a fiber-rich diet for your care recipient.
- Leave the toilet seat up and the bathroom door open with a light on at night.

Reproductive System Changes

Women. The effects of age on the reproductive system are of special interest to humans, not only because of physical changes, but also because of the psychological impact which influences self-image. In the female, **menopause** —which occurs in the late forties—is the cessation of the menstrual cycle and marks the end of child-bearing years. During and following menopause, the ovaries become inactive with eventual cessation of egg production and a loss of estrogen and progesterone synthesis. Mechanisms responsible for this ovarian shutdown are still unclear. With the drop in circulating estrogen and progesterone levels, changes occur in uterine and vaginal tissue and a decreased level of vaginal lubrication.

Men. In the male, there is no set time of reproductive change such as menopause, but there are gradual changes in the structure and function of reproductive organs. Between the ages of 50 and 90 there is a slow decline in circulating levels of testosterone. There is continued sperm production well into old age, even though the rate of production and the number of active sperm decline. Age-associated deterioration of organs responsible for semen production result in a decreased volume and thickness of seminal fluid. Particularly affected is the **prostate gland**, which after the age of 40 begins to show degenerative changes. Also, the gland generally increases in size and becomes a frequent site of cancer in the aged. The average middle-aged man takes two or three times as long as the average young adult to achieve an erection, although as discussed below, this seldom has a serious effect on sexual activity.

Sexual activity. Can sexual activity be maintained into later years? Yes! Studies show that sexual desires and capabilities continue into later life and that sexual activity can be maintained by men and women well into their seventies and eighties. The changes in the reproductive system discussed above are not usually the cause of reduced sexual activity in old age. In fact, a major reason for reduced sexual activity for older adults, especially women, is the lack of a suitable partner. In men, the fear of losing sexual ability is often a major cause of **impotence** (the inability to maintain an erection). Consulting with a physician can determine if the impotence is due to physical, situational, or psychological causes or, as is often the case, a combination of causes.

Many individuals who have **heart disease** fear that sex might cause a heart attack, and, therefore, they avoid sex. In general, sexual intercourse can be resumed several months after a heart attack, depending on the degree of recovery. There is some evidence that sexual activity, as with activity in general in the months following a heart attack, can help maintain the body in good condition. Be sure to consult your physician, however, rather than following the general guideline presented here.

Many other physical problems can interfere with sex. These include: diabetes and prostate operations in men; mastectomy, hysterectomy, and urinary infections in women; and colostomy and ileostomy in men or women. Most are treatable. If your physician cannot treat you, he or she will direct you to other specialists who can. Occasionally, however, a physician does not view the issue of sex as important enough to warrant treatment. If comments like "Well, what do you expect at your age?" are made by the physician, you might want to consider seeking other advice.

Hormonal and Immune System Changes

Most hormones of the body, which affect everything from general metabolism to behavior, are secreted by glands of the endocrine system. With aging, there may be an alteration in the production of a hormone or in its action. Two endocrine glands that have received considerable attention by gerontologists are the pancreas and thymus.

Diabetes. One function of the pancreas is to release insulin in response to blood glucose, thereby lowering blood sugar levels. As early as the fourth decade of life, there is a reduction of glucose tolerance such that when glucose is ingested by an older person, the blood sugar level increases to a higher point and takes longer to return to normal than in a younger person. It may be that the pancreas is less sensitive to the sugar stimulus or that less insulin is secreted by the older individual. This decline in glucose tolerance may be related to the age-dependent incidence of maturity-onset diabetes (type II diabetes).

The aging immune system. The thymus gland, located behind the breastbone, is now known to be a key organ in development and probably also in aging of the body's immune system. After peaking in functional activity at about age 12, the gland diminishes in size and hormone output. With the decline in thymus hormones, there is a subsequent decline in activity of two types of blood cells (called T- cells and B-cells) that play an important role in our body's defense mechanisms. As a result, the T-cells and B-cells are less able to recognize and attack invading organisms or foreign proteins.

This disruption of the T-cells and B-cells could also result in an increase in antibodies that are directed toward the body's own cells, which can result in **autoimmune diseases** such as hemolytic anemia, rheumatoid arthritis, or systemic lupus erythematosus. This increase in autoimmune reactions with aging could also be related to the increased incidence of diabetes, atherosclerosis, and deposits (called "plaques") in brain tissue.

Nervous System Changes

Nerve cells. The nervous system is composed of the brain, spinal cord, and peripheral nerves that carry messages to and from the brain and the rest of the body. A person is born with all the nerve cells he or she will ever have, which means that the ones that are remaining at death are the same age as the person. Perhaps more important than age changes in the number of nerve cells are age changes in how nerve cells are structured and in the way they work. As you age, various parts of your nerve cells deteriorate, and they become less efficient. This results in some overall loss of speed in receiving, processing, and sending nerve signals. There is also a very obvious loss in reflex and reaction times with age. In general, elderly people are slower on tasks that emphasize the senses, perception, and muscle movement (such as eye-hand coordination) or that require quick response time.

Neurotransmitters. Neurotransmitters are the chemicals that allow nerve cells to communicate with one another. Changes with age in neurotransmitters might also affect the working of the brain. Some research shows that with age, neurotransmitters might not be produced as readily by the body or they might become less effective. Interestingly, it is the loss of the neurotransmitter dopamine in a certain part of the human brain that causes **Parkinson's disease**. And, **Alzheimer's disease,** which affects less than 10% of the population over age 65, is linked with a decrease in the chemical necessary for making the transmitter acetylcholine. These diseases, however, are certainly not considered part of the normal aging process, but they do show the important role played by neurotransmitters.

Sensory Losses

The senses—including vision, hearing, taste, smell, and touch—are also part of the nervous system and show a decline in later years. An understanding of the effects of sensory losses in older adults will lead to a much greater understanding of the person you provide care. The following box summarizes some of the major changes. Additional information on the effects of sensory changes is in other chapters in this manual: The effects of sensory changes on communication are discussed in Chapter 5 on *Techniques for Aiding Communication.* Changes in taste and smell are discussed in Chapter 7 on *Nutritional Needs.*

Diseases

While it is not possible to include detailed information about the various diseases in a manual of this size, the next box contains summary statements about the common diseases affecting older adults. Please consult your physician to find out what the disease is, how the person will be affected, what treatment is given, and what is the expected outcome (prognosis). After conferring with the physician, you may want to contact one of the sources listed in Chapter 12 for more information.

CHANGES IN THE SENSES WITH AGE

Vision: In the eye, the lens may stiffen, making it harder to focus on objects. The lens may also yellow, causing certain colors to look faded. With less light passing through the lens, glare becomes a problem, and it takes longer to adjust the eyes from bright to dim light and vice versa. The inability of the lens to focus on near objects often leads to the need for bifocal or trifocal glasses.

Hearing: Hearing loss is common in older adults. An older person usually experiences loss in the ability to hear high frequency sounds, such as consonants. An older person also may lose the ability to hear more than one sound at the same time. Hearing gradually decreases beginning in early adulthood. Some of the loss in the later years can be avoided with proper ear protection during early years.

Taste, Smell, Touch: A decrease in the number of taste buds and smell receptors leads to a decline in these senses. Consequently, you might see an older person using more salt, sugar, or spices to maintain flavors they enjoy. A decrease in the sensation of touch can also have dramatic effects. Testing bath water, cooling liquids and foods before consumption, and using caution when there is a risk of heat injury is extremely important.

COMMON DISEASES OF OLDER ADULTS

Alzheimer's: A progressive brain disorder which causes mental confusion and eventual physical incapacitation. See discussion in Chapter 9.

Arthritis: This may refer to any one of hundreds of diseases that cause inflammation of a joint. Arthritis is not a part of the normal aging process. It is a disease.

Cancer: There are many types of cancer with varying degrees of seriousness and many different types of treatment. Over half of all cancers can be cured, especially if detected and treated early.

Diabetes: There are two major types of diabetes: Type I and Type II. Diabetes can have serious side effects; therefore, diagnosis, treatment, and compliance with physicians' orders is important.

Heart Disease: Coronary thrombosis or coronary occlusion. Heart diseases have a variety of causes and treatments.

Emphysema: This is a major lung disease often associated with smoking. Anyone with this disease should not smoke or be around individuals who are smoking.

Osteoporosis: A gradual thinning of bone that may result in easily broken or fractured bones. Hip fractures are commonly associated with osteoporosis. Dowagers hump (hump back) indicates that the spine is affected. Women are especially vulnerable to being afflicted with osteoporosis.

Parkinson's Disease: A progressive neurological disorder which is characterized by tremors, slow speech, and rigidity in the muscles.

Stroke: Stroke results from a blood clot or hemorrhage from a blood vessel in the brain. Some type of neurological symptoms often result, depending upon where the injury to the brain occurs.

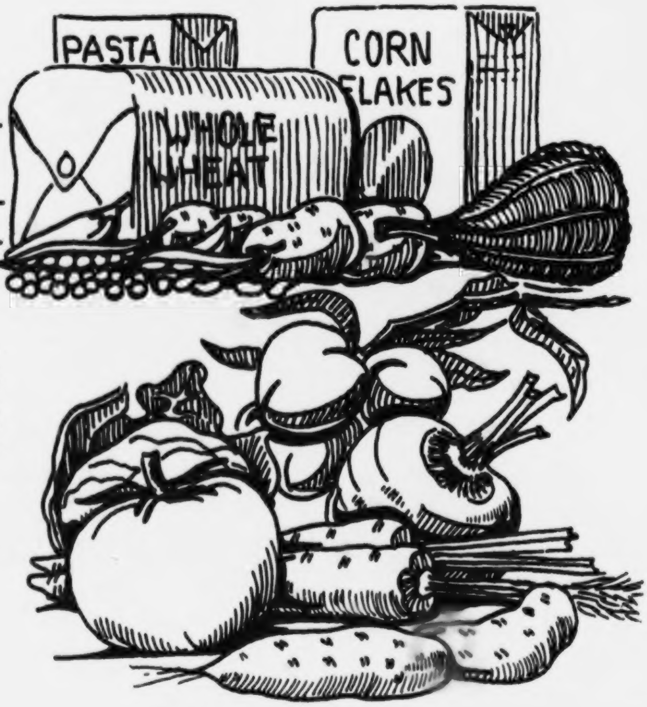
Summary

In this chapter we have discussed age-related changes in the various body systems and have emphasized the importance of distinguishing between changes that result from normal aging and those that occur due to disease. Since the rate of these changes varies a great deal between individuals, it is important not to make generalized statements about older people. If you suspect that the opinion given by someone (such as your physician) might be influenced by generalizations or negative attitudes towards older people, we suggest you consider seeking advise about your physical condition from another source.

Chapter 7

Nutritional Needs

Barbara Adams
College of St. Scholastica



The Meaning of Food

What does food mean to you? Is it just a source of fuel that keeps you going, or is there something more to food? Think about this as you read about Mr. Johnson:

- **Mr. Johnson is a 78-year-old retired steelworker who has lived in the same small town his whole life. Since his wife's death several years ago, he has been withdrawn and lonely. They were married for 52 years and she had always done the household chores. Since his wife's death he uses his kitchen very little because it brings back memories. His refrigerator contains some beer, a box of crackers, some butter and a jar of herring. He goes out to eat several times during the week, but the food doesn't taste like it did when his wife cooked it.**

For most of us, as it is for Mr. Johnson, food is not just a source of fuel. For many people food has a special meaning. Our lives, our behaviors, and some of our deepest feelings may stem from associations with our loved ones and food. Food makes an occasion, food gives pleasure, and in many instances food means love. What we eat, therefore, may be closely tied to our emotions and to other aspects of our life that affect our appetites and hunger.

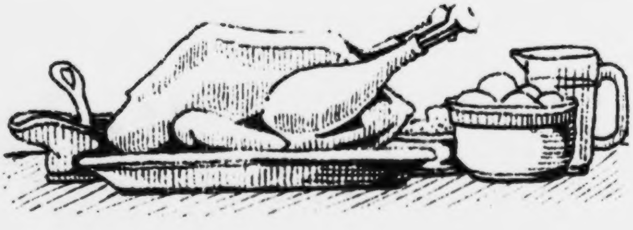
Aging can influence the types and amounts of food eaten. Thus, this chapter will give you, the caregiver, information about meals for older persons. But remember as you are reading the chapter, that much of the information applies to your diet, too!

Age Changes that Affect the Way We Eat

Changes in the body. As we age, we notice changes in our body. We might be eating about the same amount of food (or less) as when we were younger, but the pounds seem to be adding up. Or we might think that food does not taste as good as it did when we were younger: "When Mom made potato salad, it was always good; now no one can make it like that anymore." In the next box are some common changes seen in aging that affect the way we eat or the way that food is used in our bodies. Turn to Chapter 6 for information about other changes in the body that occur with aging.

CHANGES IN THE BODY

- Body fat increases while the amount of muscle decreases. This results in our burning fewer calories.
- Because our mobility decreases, we burn up fewer calories.
- Bones may get weaker, especially with no exercise.
- Dental problems, including tooth loss, may develop and reduce the ability to chew. Dental problems can be greatly reduced by brushing teeth, by rinsing or swabbing the mouth, and by checking for proper denture fit.
- The sense of taste decreases.
- The mouth may be dry because the flow of saliva decreases, making it more difficult to chew and swallow.
- Digestion problems like gas, heartburn, diarrhea, and constipation may increase. Choosing foods that do not cause these upsets may restrict the diet.
- Some physical conditions require special or therapeutic diets. For example: diabetic, low-sodium, or low-calorie diets.



Psychological and economic factors. Some things that affect what we eat are not due to bodily changes but are related to our emotional state, social contacts, or financial situation. Some examples: Transportation problems make grocery shopping difficult. Living on a fixed income makes it harder to afford proper food. Loneliness or boredom can lead to poor appetite, or cooking for one may not seem worth the trouble. Memory loss or depression may prevent people from realizing or caring about how poorly they are eating.

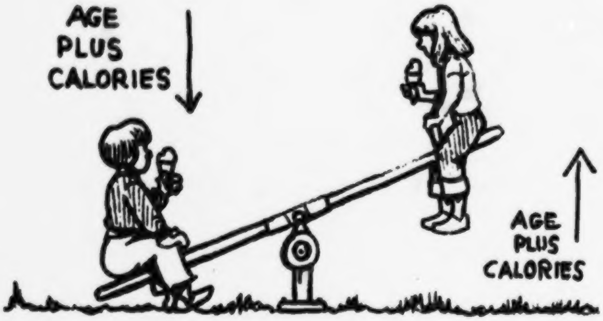
Cooking when living alone. Persons who prepared meals for a large family sometimes find it more difficult to cook for one, and food preparation can sometimes be difficult for men who have traditionally not learned to cook. But, meal preparation does not have to be a major chore, nor do you need to be a gourmet cook to prepare and serve a balanced diet. Some suggestions are listed in the next box.

COOKING FOR ONE

- Though there is controversy about the use of **processed foods,** certainly eating canned or fast foods are better than not eating enough.
- Preparing simpler foods at home and eating one meal a day at a **restaurant** that serves "home cooked" meals may be your solution.
- Another possibility may be to prepare large quantities of food, and **freeze** part of it for a later time. Don't make the mistake of eating the same thing for several days in a row, however.
- One meal a day at a **senior nutrition center** or a **home-delivered meal** while preparing other small meals at home may be helpful in obtaining proper balance in your diet.

Choosing Your Calories

Most of us need the same amount of *vitamins and minerals* when we get older as when we were thirty. However, we do not need as many *calories.* We must, therefore, choose our calories wisely. We should choose "nutrient dense" foods; that is, foods that contain lots of vitamins and minerals and not too many calories. In general, foods that are high in fats and sugars are higher in calories and do not contain many vitamins and minerals. We all need (and like) a little fat and sweet in our diets, but most of us ought to get much less than we do! Choosing foods that are lower in fat and concentrated sweets usually means that you will be getting more nutrition for fewer calories.



Nutrient density also means making the calories count. For instance, a half-cup of soda pop and a half-cup of orange juice have approximately the same number of calories. The pop contains almost no vitamins or minerals. The juice contains vitamins A and C, B vitamins, potassium, and other minerals such as zinc. So the nutrient density of the orange juice is much higher than the pop. The same goes for milk, especially low-fat milks; you get a lot of nutrition for your calories.

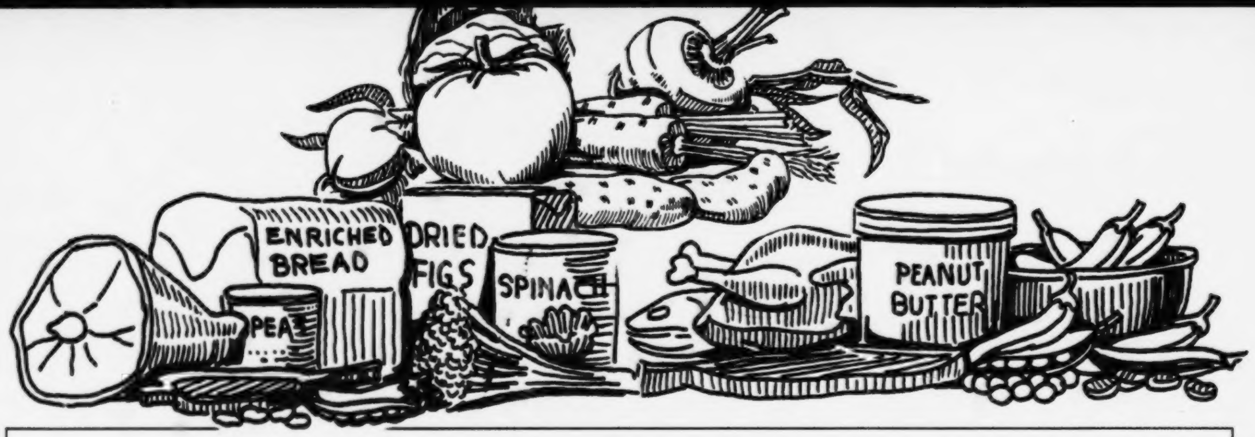
A question for you: What would be more nutrient dense: 1/2 cup tapioca pudding made with skim milk or 1/2 cup plain gelatin dessert? Answer: The tapioca has more nutrition (because of the milk) for about the same calories. . . around 100.

ORANGE
JUICE
MILK
MILK
COFFEE

Balanced Meals

It is difficult to know all about nutrition, but you can get a good idea about a healthy diet by using the guides that have been developed over the years. One of the guides that is easiest to use is the **Four Food Groups.** You will find that not everything you eat fits neatly into these groups, but if you are choosing the majority of your foods from these groups, the nutrient density of your diet will be very good.

You have seen the Four Food Groups many times before. See the next box for a list that tells you the nutrition you get from the groups and how many servings an adult should get each day from each group.



THE FOUR FOOD GROUPS

Food Group	Minimum per Day Servings Recommended after Age 60.	Examples of One-serving Portions
Milk and Milk Products	2	1 c. (8 oz.) milk, yogurt. 1 1/2 oz. cheese. 1 1/2 c. cottage cheese.
Meat	2	2-3 oz. cooked, lean meat, fish, poultry. 2 eggs. 4 tbsp. peanut butter. 1 c. cooked, dried peas, beans or lentils.
Fruits & Vegetables (total 4 servings daily; including citrus and dark-green leafy and deep orange vegetables)	1-2	Vitamin C rich: 4-6 oz. citrus juice. 1 orange. 1/2 grapefruit or cantaloupe. 2 boiled potatoes. 1 c. raw cabbage.
	1-2	Vitamin A rich: 1/2 c. carrots, broccoli, spinach, greens, sweet potatoes.
	1-2	Others: 1/2 c. potatoes, green beans, peas, corn, apples, banana, peach, etc.
Bread & Cereals	3-4	1 slice enriched or whole grain bread. 1 oz. (3/4 cup) dry cereal. 1/2 to 3/4 c. cooked cereal. 1/2 c. enriched noodles.
Miscellaneous		Margarine, butter. Desserts. Sweets, candy.

For a balanced diet, you should choose from several of the groups each time you eat. This may sound like a lot of work, but the easiest way to eat a good diet and save time is to plan a "menu cycle" (menus for a week or two). An example is shown in the next box.

A TWO-WEEK MENU CYCLE FOR A LARGE MEAL

S	M	T	W	TH	F	S
FIRST WEEK:						
pork potato carrots	lentil spaghetti	meat loaf potato green beans	fish rice broccoli	soup muffins	stir-fry (chow mein) fried rice	tuna hotdish salad
SECOND WEEK:						
beef potato cabbage	hamburger hot dish	soup muffins	pasta (with ground turkey)	beans rice salad	fish baked-potato coleslaw	chicken rice/pasta mixed vegetables

The two-week cycle is flexible; you can change the way you prepare the foods. For example, you could roast the beef, make homemade mashed potatoes and coleslaw (Sunday, week two) or, if you were tired, you could cut up the beef, the potatoes and cabbage, throw them in a pot with a little liquid, and make a one-pot stew. The example is for two weeks of large meals. You could plan the same for two weeks of small meals and two weeks of breakfasts.

The **beverage** you choose is up to you; be sure to include at least two servings from the dairy group each day. Milk is a good way to get your calcium, but if the person you are caring for does not like milk, make it into a cream soup with low-fat milk, or make a low-fat milk pudding. You can also add nonfat dry milk to other foods (stir in 2 to 4 tablespoons of dry milk powder into mashed potatoes, soups, beverages, casseroles, etc.). This adds protein, calcium, and many other vitamins and minerals, and it works very well for a poor eater who will not eat a sufficient quantity at meals.

Light meals could be much like breakfast; there is no rule that says you must eat a particular food at a particular meal. If you feel like having leftover spaghetti for breakfast, that is fine. You have a protein food (the hamburger or beans), a starch food (the spaghetti noodles), and a fruit or vegetable (the tomato sauce). If you want a bowl of cereal for lunch, that is fine too. Top it with some fruit for a good, light meal. Just remember that variety is the most important part of a good diet.

There is much discussion about when to eat **the biggest meal** of the day. Nutritionists recommend that your largest meal be at noon. This is to give yourself time to digest the meal and burn off some of those calories. As we age, having a large meal before we lie down invites a sleepless night.

A wonderful book that may be helpful in providing you with information and new ideas about food choices is *Food For Fitness After Fifty* by Stare and Aronson.

Special Diets

The older we get, the more likely it is that we will be told to alter our diet in some way. The doctor may have advised reducing salt or fat. Maybe the dietitian said a change in eating habits would help treat diabetes or that an increase in fiber may help prevent constipation. Use caution so that you do not go to extremes in any diet. Too much of a good thing is not good. Your doctor can refer you to a Registered Dietitian if you have specific questions. Remember, any special diet should be planned on an individual basis. **Moderation** and **variety** are the key words. You should not be eating the same thing day after day just to stay on a so-called "diet."

If you are caring for someone who has **diabetes**, you should be sure to understand the diet requirements, as explained by your doctor or dietitian. Be cautious when you shop. Do not be caught by the special "diet/no sugar" candies, ice creams, etc. Often they are very expensive, and sometimes they contain more calories than their regular, sweetened counterparts.

If you are on a **low-salt diet**, the tips in the next box can help you avoid high-sodium foods.

HOW TO TELL IF FOOD HAS A LOT OF SALT (SODIUM)

- Salt is part of the name: garlic salt, onion salt, lite salt.
- Sodium or compounds high in sodium (such as Accent, baking soda, baking powder) are among the ingredients listed first on the label.
- You can see salt on the food.
- The food depends on salt to preserve it: bacon, salt pork, sausage, cured ham.
- The food is in brine: sauerkraut, pickles, fish.
- The food tastes salty: luncheon meats, sardines.

DIET
ICE CREAM

There are many tasteful suggestions for improving the flavor of meals for a person who has had to cut certain things (such as salt) out of his diet. The following herbs, spices, and other flavorings can be used to add flavor and zest to foods without adding sodium: nutmeg, onion, scallions, sage, thyme, bay leaf, mint, garlic, dry mustard, rosemary, curry, ginger, paprika, lemon juice, mushroom, sherry, pepper, parsley, dill seed, chives, green pepper, mace, cinnamon, basil, oregano, allspice, cloves, and vinegar. Of course, you will want to be sure that the suggested herbs, spices, and other flavorings may be eaten by the individual.

Alcohol

As people grow older, their tolerance to alcohol decreases, and the harmful side effects increase. Some think that a *small* bit of wine or beer may stimulate appetite or help one to sleep, and alcoholic beverages are often used for that purpose. But when abused or when used to the extent that other foods are excluded, alcoholic beverages can be harmful, especially in the aged. Every ounce of liquor provides about 75 calories; beer about 150 calories per 12 ounces; wine about 75 calories per 3 ounces of dry and 130 calories per 3 ounces of sweet. To someone who only requires 1,200 calories per day, a beer would give 12 percent of those calories and contribute little in the way of nutrition. Alcoholic beverages are extremely low in vitamins and minerals, and they provide practically no protein. In fact, to burn alcohol in your body, you use up valuable vitamins such as thiamin (vitamin B1).

Medications

Older persons, who take three times as many medications as the population in general, are particularly vulnerable to the adverse nutritional effects of drugs. While the medication may be necessary to treat a condition, it may cause unpleasant side effects like dry mouth, change in appetite, upset stomach, or constipation. On the other hand, food can also affect the action of a drug in some situations.

Always ask your doctor or pharmacist about (a) side effects that might be associated with your medications, (b) drug interactions that might occur with other medications or food, and (c) when and how to take your medication. But, do not stop taking a drug without telling your doctor. As a consumer, it's extremely important to fully understand your particular medical condition and medications. Your physician or pharmacist will be able to help you. Never be afraid to ask questions.

In the next two boxes are some tips to help in case you experience **side effects** when taking a medication.

WHAT IF YOU EXPERIENCE HEARTBURN, GAS, NAUSEA, OR VOMITING?

- Eat small quantities of food at frequent intervals.
- Control or avoid using alcohol, coffee, tea, and other caffeinated products. Even decaffeinated coffee can cause heartburn.
- Avoid highly acidic foods such as orange juice and tomato products.
- Avoid gas-forming foods (these vary among individuals).
- Chew food slowly with mouth closed.
- Do not mince or puree food.
- Eat crackers, dry toasted bread, or dry cereal to relieve nausea.
- Drink cold, clear beverages, or juices for nausea.
- Reschedule mealtimes if nausea occurs at consistent times each day.
- Your doctor will want to know if you are nauseated especially if you are taking a digitalis medication; nausea could be a sign of toxicity.

WHAT IF YOUR MOUTH IS DRY AND SORE?

- Moisten (dunk) dry foods in beverages.
- Decrease your use of dry or salty foods or snacks.
- Eat moist, soft-textured foods such as mashed potatoes or milk toast.
- Avoid spicy, highly acidic foods such as tomatoes, oranges, pineapple.
- Suck on ice chips, or eat cool foods such as sherbet, melon, cold milk.
- Avoid using highly sweetened foods or liquids such as soda pop.
- Maintain good oral hygiene.
- Use lemon/glycerin swabs to clean and freshen the mouth.

Weight

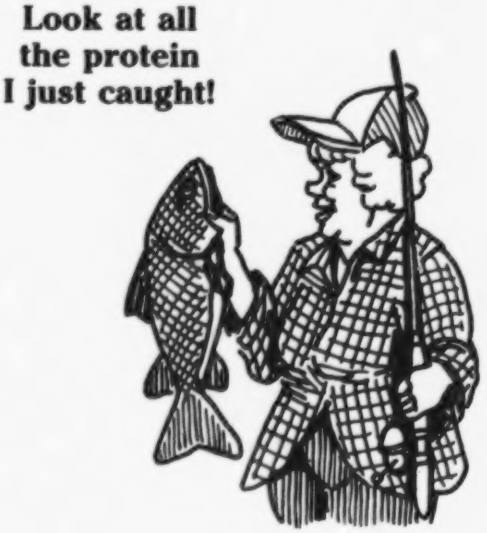
As we mentioned before, weight can creep up with age. It is difficult to lose weight at any time, but it is especially difficult when one is older. The Four Food Groups guide (presented in a box earlier in this chapter) would be a good weight-loss diet also. You can get the needed nutrients and still be eating only about 1,200 calories a day, especially if you choose low-fat meats and dairy products. Take it easy on the sauces, fats, and oils, and use fruit for dessert.

Don't fall for gimmicks either. A good weight-loss plan should not be expensive and should not be a quick fix. Over-the-counter **weight loss medications** are not effective for successful long-term weight control. Furthermore, they are definitely not recommended for many older adults because they may interact with other medications and are dangerous for people who have diabetes, hypertension, and other health conditions.

Avoid **starvation diets.** Weight is more easily managed with regular meals. Skipping a meal only makes us eat more at the next one. A skipped meal or going without food for long periods can actually trick your body into burning *fewer* calories!

True or False? Certain fruits and vegetables have "negative calories" and will actually help burn the fat off of your body. FALSE!! This is a popular myth which has no scientific basis. If you eat half a grapefruit you will get 50 calories of energy. The key to losing weight is EATING LESS and MOVING AROUND MORE. There are no easy solutions.

A big help in weight loss is **activity**. If you or the one you care for can move around, you will burn extra calories. That does not mean you should go out jogging, but it might mean walking if possible. Standing is better than sitting. A stroll around the living room is a start! If you would like more information about exercise, turn to Chapter 8 on *Exercise for Fitness.*



Vitamin Supplements

Sometimes it is advisable to take a vitamin/mineral supplement. Those who cannot eat enough or have very restricted diets might need a supplement. Never start taking a supplement without first asking your doctor, because your medication might be affected by a particular vitamin. If you are told that you need to increase certain vitamins or minerals, the next box can help you select foods that are especially good sources of potassium, iron, and calcium.

GOOD POTASSIUM SOURCES

potatoes
fish
meats
tomato (whole or juice)
legumes (dry beans, peas, lentils)
grapefruit or oranges (whole or juice)
most fruits & vegetables
nectarines
figs
prunes
cantaloupe
soybeans
dates
bananas
avocado

GOOD IRON SOURCES

beef, pork, lamb
prune juice
deep green, leafy vegetables
shellfish (clams, oysters, shrimp)
organ foods (liver)
legumes
iron-fortified cereals

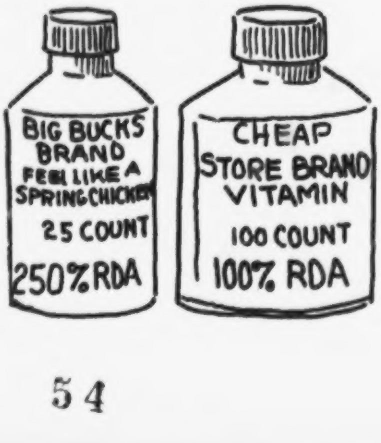
NOTE: It is important to have sufficient vitamin C (ascorbic acid) in your diet to help absorption of iron.

GOOD CALCIUM SOURCES

milk (whole or skim)
cheese, yogurt
custards or milk-based foods
deep green, leafy vegetables
  (spinach, turnip greens, etc.)
canned sardines, salmon (bones)
farina (cooked)
broccoli (cooked)

MILK
COTTAGE CHEESE
SALMON WITH BONES
SARDINES

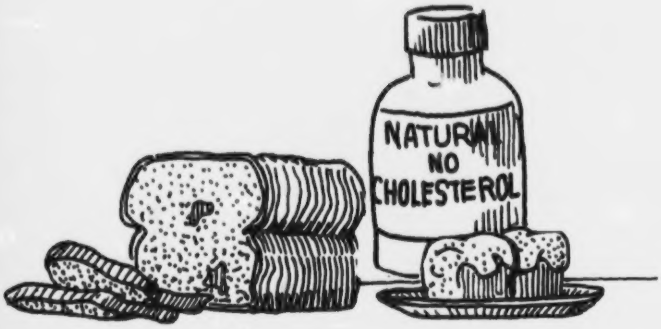
If your doctor feels a supplement is necessary, you do not need to spend a lot of money on a brand-name vitamin. Don't spend your budget on a bottle of vitamins. Many store-brand or generic vitamin/mineral supplements are just as good. Look for one that provides no more than 100 percent of the recommended daily allowance (RDA). Buying a product that provides 250 percent or more is simply wasting your money. Many water-soluble vitamins are excreted in your urine if your body does not use them up each day, while others are stored in the body and could be toxic at high levels.


BIG BUCKS BRAND
FEEL LIKE A SPRING CHICKEN
25 COUNT
250% RDA
CHEAP STORE BRAND VITAMIN
100 COUNT
100% RDA

Health Claims

Labels proclaim why you should buy the products. Be wary of claims that seem too good to be true or labels that try to trick you into buying a product because it is "natural" or contains "no cholesterol." When you are shopping, keep in mind that only animals and humans can make cholesterol. So if you see a label on an "all vegetable" product that says "no cholesterol," that is a true statement, but it couldn't contain cholesterol anyway if it is all vegetable. We are afraid of cholesterol, and manufacturers know that we are more likely to buy a product if it says "free of cholesterol."

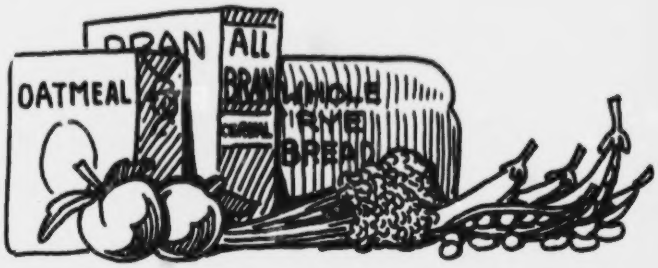
This is especially bad if the cholesterol-free product is a fat or oil. Recent research indicates that, possibly, we should be more concerned with reducing our total fat and saturated fat intake than with cholesterol in our food. Saturated fats are those that are solid at room temperature. Fats from meats, butter, and poultry and those that were made solid, like shortenings, are primarily saturated fats. High intake of fat and saturated fat is connected with increased fatty deposits in blood vessels.



Dehydration and Constipation

Fluids are extremely important for anyone, but especially for older adults. They are less able to cope in situations that take water out of their bodies. Heat, fever, diarrhea, and vomiting can deplete fluids rapidly. Normally a person needs from four to six cups of fluids each day. That includes milk, juice, tea, coffee, water, and other liquids. Because coffee and tea seem to have a mildly diuretic (liquid elimination) effect on the body, it is best to get fluids from other sources.

Constipation can be a problem if we do not get enough fluids. Simply drinking a cup of warm water in the morning may help solve constipation problems. Activity helps, and so does dietary fiber. When adding fiber to any diet, do it gradually. When you are not used to fiber, gas and bloating from a sudden load can be very distressing. When adding fiber to your diet, be sure to include adequate fluids.

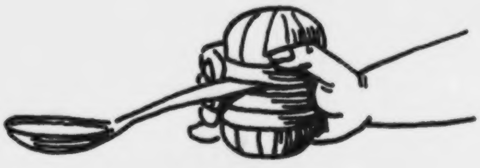


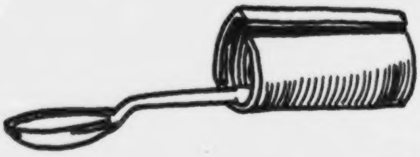
GOOD SOURCES OF FIBER

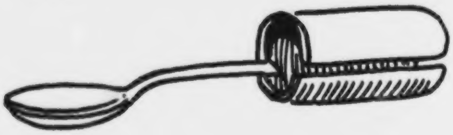
- whole grain cereal (bran, oats, etc.)
- whole grain bread
- vegetables
- legumes
- fruit
- soups (homemade)

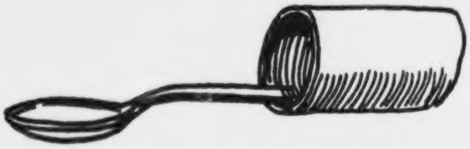
Helping the Physically Impaired

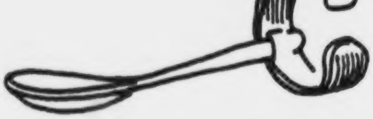
There are many aids available to help your loved one be independent at the table. Pictured are some appliances that can help in food preparation and in eating. Sometimes, just using a plate with a high edge can help the person scoop the food onto a spoon or fork. Divided plates, cuff spoons, and many other helpful utensils can be purchased or ordered through special catalogues or hospital supply stores. Being able to feed oneself or help prepare the food will enable the person to feel more independent. Think about how it would affect your appetite if you were unable to feed yourself. To have a better understanding of this, you may want to try having someone feed you a meal.

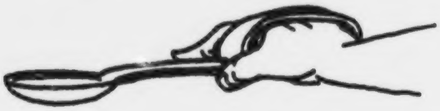


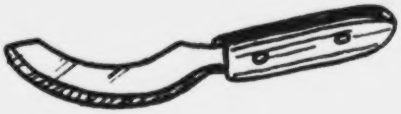


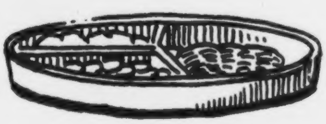


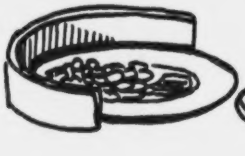


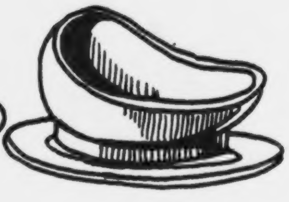


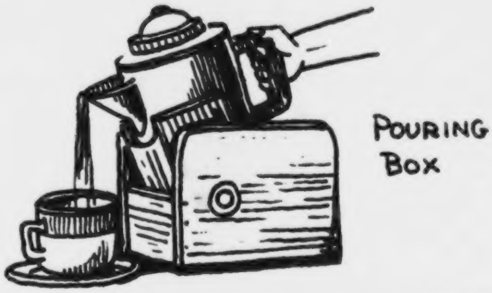








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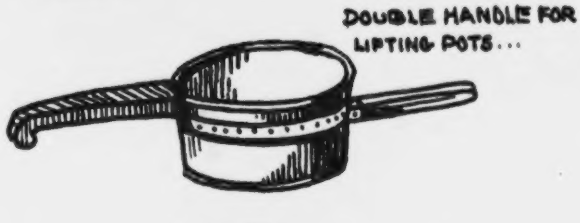
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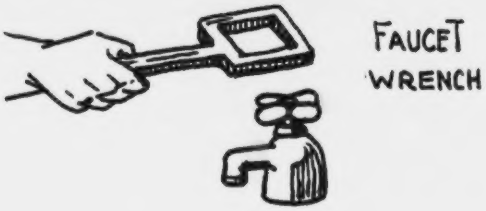
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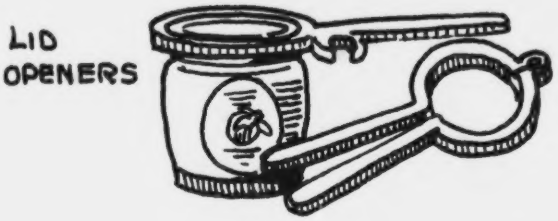
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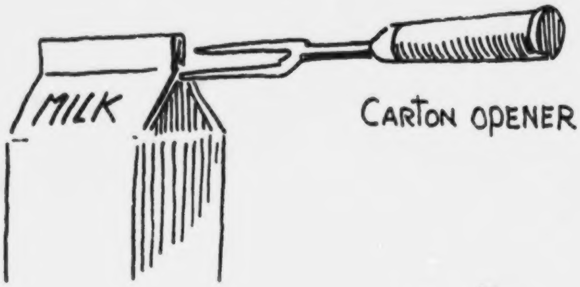
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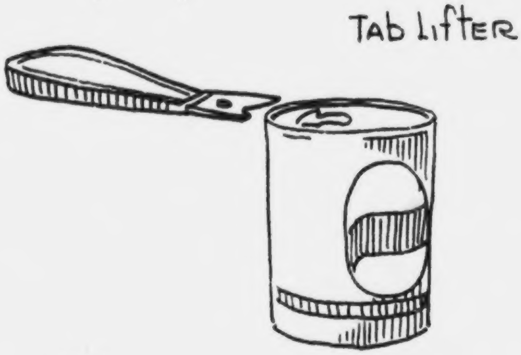
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Memory Impairment— Hints for Mealtimes

When the person you are caring for has forgotten how to chew or swallow, or has a slow reaction time, you or one of the family members should be nearby when that person is eating or drinking, because there is a danger of choking. Your alertness can prevent this. Learn to perform the **Heimlich maneuver** to relieve choking. The Red Cross, your doctor, or nurse can teach you this important procedure.

With slowed reactions, do not rush meals. Be sure the food is chewed well and swallowed. If there seems to be a problem with choking on liquids, offer thickened liquids like pureed soups, puddings, and gelatins. There are products available to stir into liquids. "Thick-It" is one such product. Ask your doctor or pharmacist for information about it. If the person you are caring for has forgotten how to feed himself, or is having difficulty with coordination, try helping him to relearn the activity. Put food on the spoon in his hand, and gently assist him with putting the spoon into his mouth. Remind him to chew and swallow. Repeat this, and give lavish praise as you see him become more independent. This will help him relearn the skill.

Serve liquids and soups in a cup so that they are easier to handle. Be sure to cool hot liquids to avoid burning the mouth or tongue. Older people have a decreased sensitivity to hot and cold. Special precautions should be taken with memory impaired persons who may not be able to recognize the temperature of a liquid.

Limiting the number of foods offered at one time and serving one part of the meal at a time may also reduce confusion. Serving one-dish meals and limiting the number of utensils may also be useful. Often a spoon will do for the whole meal.

Finger foods are a great help for anyone who has difficulty handling utensils. Sandwiches or foods that can be wrapped in a piece of bread are easy to eat.

Do not put inedible objects close to a memory-impaired person when he is eating. Colorful objects especially may be mistaken for food.

Sometimes, memory impairment causes people to forget that they have just eaten. This can cause two different kinds of problem. First, if you give them something to eat each time they ask, you could be endangering their health by causing weight gain. On the other hand, they might forget to eat or refuse to eat.

It is important to contact the physician if the person you are caring for stops eating, especially if she becomes dehydrated (not enough water in the body). Be sure to offer liquids if no solid food can be taken. If you can get her to take liquids, make the liquid as nutritious as possible.

Meal Schedules and Appetite

It is difficult, with our busy lives, to always stick to a schedule for meals. A regular schedule, if possible, might not only lead to better eating habits, but you might also find that you can manage your precious time more efficiently. Skipped meals or late meals do not help an already poor appetite. But, be aware that a rigid schedule may not be the answer for everyone. For example, you may be caring for someone who is a very poor eater, whose appetite peaks occasionally at midmorning. By taking advantage of such periods of increased appetite, you may actually be able to stimulate a better appetite at mealtime and move to a more regular, less disruptive schedule. Forcing someone to eat just because it is mealtime, will only hurt your relationship. One skipped meal is not that important. Sometimes older people cannot tolerate three large meals and find frequent smaller ones easier.

LOSS OF APPETITE OR ALTERED TASTE

- Vary color, texture, and temperature of foods served at meals.
- Serve favorite meals or snacks to stimulate appetite.
- Eat small, frequent meals.
- Enhance food flavors with favorite herbs and spices.
- Marinate meats in sauces, wines, fruit juices, or herbed vinegars.

Being included in the family setting at meal times as well as at other times is important. If the individual you are caring for needs a great deal of assistance, you may choose to feed her first, then get her settled comfortably before you eat. If this works best for you (and other family members), then do it. It may be a good idea to have the person join you for a morning or afternoon snack. In this way, you may both benefit from the togetherness without the hassle of food preparation and cleanup.

Summary

A good, nutritious diet does not have to be expensive, boring, or tasteless. **Variety, moderation,** and **activity** are the three most important words in your diet vocabulary. If you are confused or unsure of what you should be doing, ask your physician, a Registered Dietitian, or a Registered Nurse. You have the right to know how to be healthier and how to help the person you are caring for to be healthier!

Chapter 8

Exercise for Fitness

Annette Caruso-Howatt
College of St. Scholastica

What Regular Exercise Can Do

This chapter tells you how 15 to 30 minutes of physical activity 2 to 3 times a week can help you as a caregiver. It gives you "key facts" (in boxes) to remember during activity and presents four different exercise programs for you to choose.

You can improve your own quality of life and that of your older relative or friend through regular physical activity. Exercise or participation in a variety of activities can reduce stress, keep you healthy, make you feel better about yourself, and give you more energy for your daily tasks.

Physical fitness through exercise and sport participation can give you a satisfying and productive life-style. The physical, mental, emotional, social, and spiritual aspects of your life will improve with physical activity. You can choose from many different kinds of physical activities. Sports such as bowling, golf, walking, table tennis, tennis, and bicycling will improve your physical fitness with regular participation. Also, stretching, aerobic and strength exercises will greatly reduce the effects of the aging process.

KEY FACT 1

Regular exercise gives you more energy to complete day-to-day tasks.

KEY FACT 2

A 15 to 30 minute exercise break can help you feel better mentally and physically.

KEY FACT 3

You can start exercising at any time during your life.

KEY FACT 4

Active adults feel better about themselves and others.

Are You Ready for Physical Activity?

The questions in the Readiness Checklist box are aimed at helping you determine if you are ready or not to begin new physical activities. Answer the questions in the box by checking "yes" or "no" for each question.

READINESS CHECKLIST

YES NO
☐ ☐ 1. Has your doctor ever said you have heart trouble?
☐ ☐ 2. Do you frequently have pains in your heart or chest?
☐ ☐ 3. Do you often feel faint or dizzy?
☐ ☐ 4. Do you have high blood pressure?
☐ ☐ 5. Has your doctor ever told you that exercise would hurt your bones or joints?
☐ ☐ 6. Is there a good physical reason not mentioned above why you should not follow an activity program?
☐ ☐ 7. Are you over age 60 and not used to physical activity?

If the answer was **YES** to one or more of the questions in the box:

- Call your family physician.
- Tell him/her what questions you answered YES to.
- Ask him/her how you should begin on an exercise program.
- Show or tell him/her the exercise programs in this manual that you want to begin with.

If the answer was **NO** to all questions and **if your physician approves,** then you may start a gradual physical activity/exercise program, such as the Walking Program in the next box. Always contact your physician first, however, before increasing your level of activity or exercise. This may be done by a simple telephone call.

A WALKING PROGRAM FOR CAREGIVERS

Week	Distance	Times a Week	Time
1	0.5 mile	3	10.0 min.
2	1.0 mile	2	19.0 min.
3	1.0 mile	3	18.5 min.
4	1.5 mile	2	26.0 min.
5	1.5 mile	3	24.0 min.
6	1.5 mile	3	23.5 min.
7	2.0 mile	3	33.0 min.
8	2.0 mile	3	31.5 min.
9	2.0 mile	3	31.0 min.
10	2.5 mile	3	38.5 min.

Getting Started

Getting started on a regular routine of exercise can be fun—and the benefits are great. A commitment to yourself to take time out of each day is needed. It may be helpful to start going for regular walks with a friend or to join an exercise group at your church, community club, or senior center. If you have special needs, you may want to check with a physician about an adapted or modified exercise program.

Four Types of Fitness

Physical fitness includes four areas: (a) muscular strength, (b) muscular endurance, (c) flexibility, and (d) cardiovascular endurance. There is a minimum and maximum amount of exercise necessary to get the health related benefits from participating in any one of these areas. First, let's see what they mean for you by looking at some more Key Facts along with some definition of terms.

KEY FACT 5

Regular exercise slows the aging process by maintaining healthy bones, muscles, and joint areas.

Muscle strength is necessary for your body to accomplish work. The ability to keep posture, walk, lift, push, and pull comes from your muscles.

Muscle endurance is the ability for a muscle or group of muscles to contract over a long period of time. It prevents undue fatigue from your work and other daily activities.

KEY FACT 6

The ability to reach, turn, twist, lift, and bend are helped by good flexibility.

Flexibility is the ability of the joints to move through their range of motion. It is different for each joint in the body. Flexibility effects your ability or inability to move easily.

KEY FACT 7

Heart/cardiovascular endurance is the most important area of physical fitness.

Cardiovascular endurance is the ability of the heart, lungs, blood, and other body systems to supply enough oxygen to the body for it to function. Other names are cardiorespiratory fitness, aerobic fitness, or circulatory fitness.

How Much Exercise Is Right for You?

There is a correct amount of exercise for each person. There is a minimum amount below which no gains in fitness will be made and a maximum amount above which it is dangerous to participate. To determine the correct amount of exercise for you, Corbin has suggested using the word **FIT**. The letters **F, I,** and **T** stand for the three important parts to consider when doing an exercise or physical activity: **FREQUENCY—INTENSITY—TIME.**

Frequency is how often you exercise. You should exercise at least three days a week.

Intensity is how hard you exercise. Exercise must be hard enough to require more work than normal. The way to measure "hardness" differs for various forms of exercise. A good rule of thumb is to work hard enough so that your breathing is faster than normal but not so hard that you cannot talk to someone else while exercising.

Time is how long you should do each exercise.

KEY FACT 8

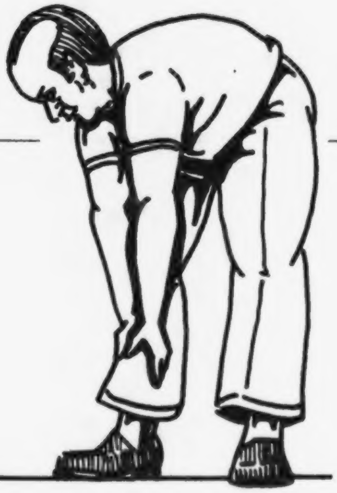
"Rule of thumb" for how hard to exercise: Work hard enough so that you breathe faster than normal, but not so hard that you cannot talk to someone.

An excellent paperback for you to use is *The New Aerobics*, by K. Cooper. This book contains many other programs especially for women. The book is available at many bookstores.

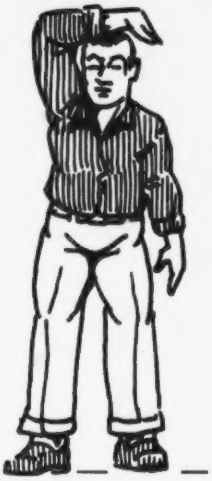
Warm Up, Cool Down!

Proper preparation can help make your exercise enjoyable, effective and safe. A warm-up prior to exercise is important. A cool-down after exercise is important. Five minutes of exercises that work on the arms, legs, stomach, neck, and back are enough. An illustration is included for each step of the following warm-up and cool-down program:

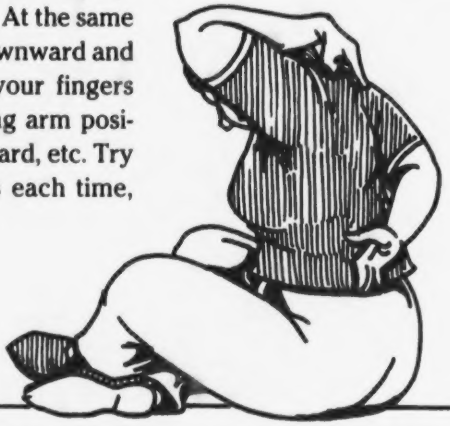
- Standing hamstring stretch. Place your feet shoulder width apart, toes pointed forward. Reach toward your ankle (right or left) with both hands, grasping as far down on your leg as possible. Keep legs straight and pull downward gently, hold for 10-15 seconds. Repeat 5 times for each leg. DO NOT BOUNCE.



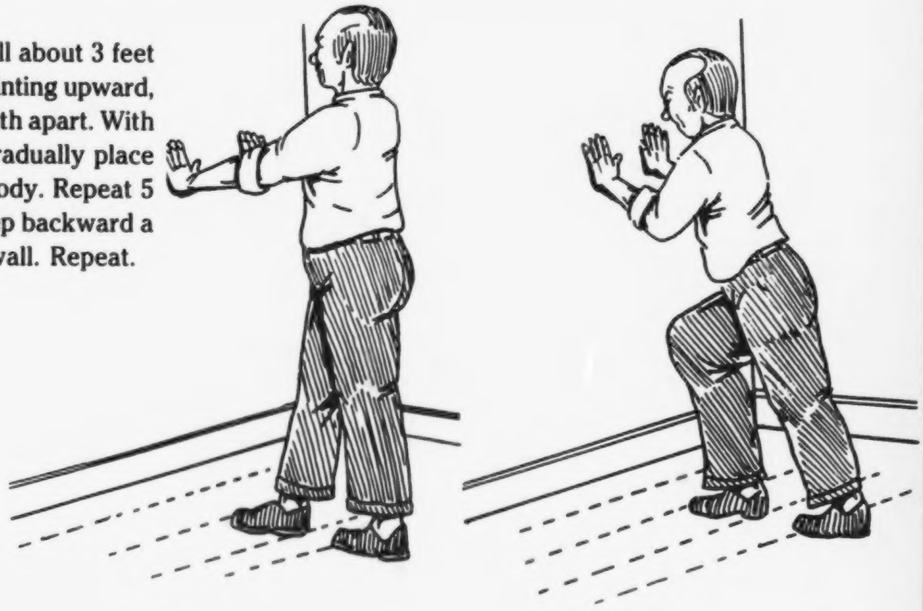
- Side stretch. With the feet shoulder width apart, lean to one side. Reach down toward the ankle with the arm on one side and up over the head with the arm on the other side. Do Not Twist or Bounce. Hold for 5 seconds, repeat to each side 5 times.



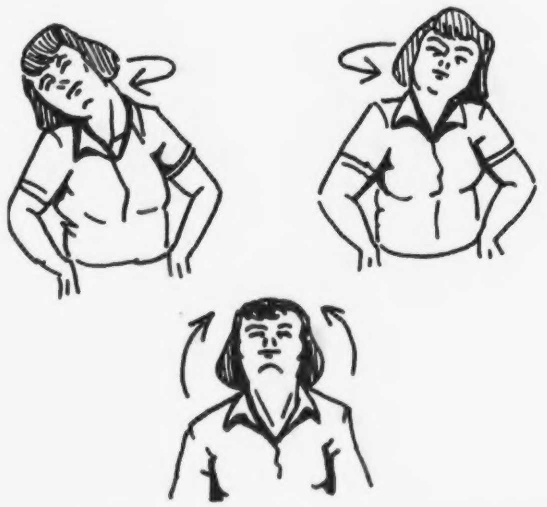
- Arm and shoulder stretch. Sit in a comfortable position on the floor. Extend your arm directly upward and then reach down your back. At the same time reach with your opposite arm downward and behind your back, trying to touch your fingers from both hands. Repeat by changing arm positions so the opposite arm reaches upward, etc. Try to touch fingers for 5 to 10 seconds each time, repeating on each side for 5 times.



- Calf stretcher. Stand and face a wall about 3 feet from it. Place your hands, fingers pointing upward, on the wall with hands shoulder width apart. With feet shoulder width apart, try to gradually place your heels on the ground, stiffen body. Repeat 5 times. Once heels touch ground, step backward a half step from the bottom of the wall. Repeat.



- Neck and head stretch. Slowly move head clockwise. Reverse the direction after you have made a full circle. Repeat in both directions 5 times.



Exercise Programs

Now that you're warmed up, let's look at exercise programs for each of the four areas of physical fitness mentioned earlier. Follow the illustrations as you read how to do each exercise.

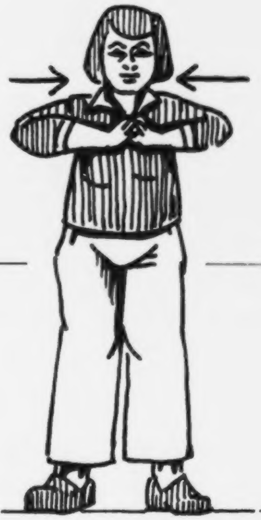
Cardiovascular Fitness Program

Frequency: 3 to 4 days a week.
Intensity: Use this rule of thumb: Work harder than normal so that your breathing is faster but you can still talk to a friend.
Time: 15 to 30 Minutes.
Activities: Bicycling, walking, jogging, dancing, swimming, hiking, continuous calisthenics, aerobic dance, rope skipping, cross-country skiing, rowing, and playing any individual or team sport.

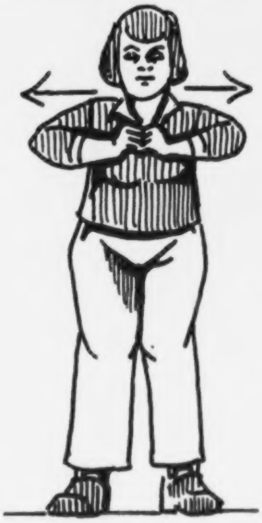
Muscle Strength Exercise Program

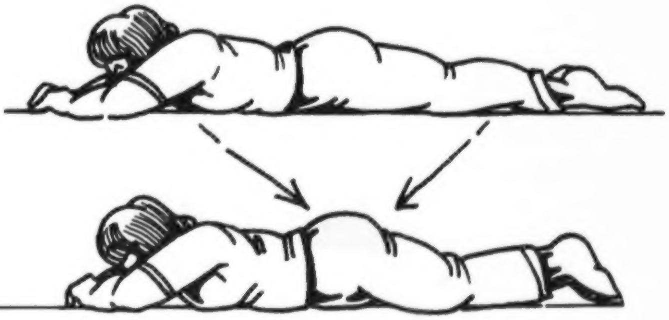
Frequency: 2 to 3 times a week.
Intensity: Follow the instructions for each exercise.
Time: Do each exercise 10 times in a row. REST. Repeat it 10 more times.

- Chest push. Put left fist in palm of right hand. Push hands together keeping arms close to chest.



- Shoulder pull. Cup hands, interlocking your fingers. Try to pull hands apart, keeping arms parallel to the floor. Pull hard.

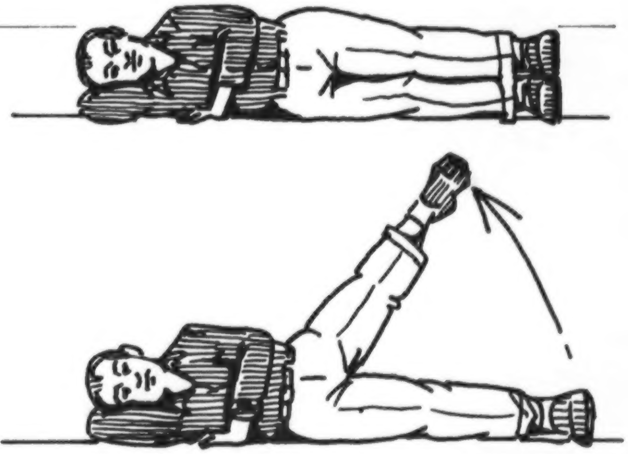




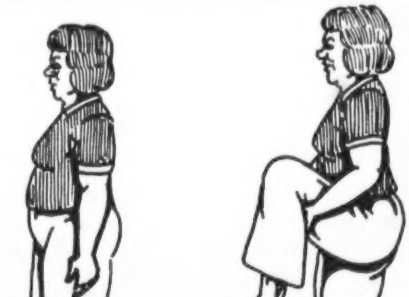
Backside pinch. Lie on floor face down. Place your legs together and pinch the buttocks together as hard as possible. Hands and arms may be placed in a comfortable position.

Muscle Endurance Exercise Program

Frequency: 2 to 3 times a week.
Intensity: Follow the instructions for each exercise.
Time: Do each exercise 10 times in a row. REST. Repeat it 10 more times.

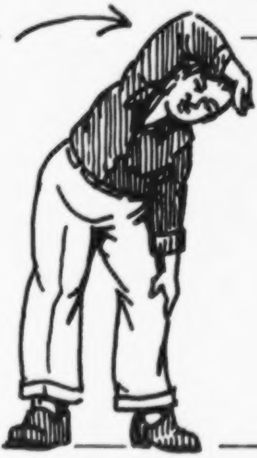


- Leg raises. Lie on side with the legs straight on the floor, place 1 arm under head (bent) and the other out in front of you. Raise upper leg until it points upward to the sky, lower slowly. Turn over to other side of body and raise other leg.

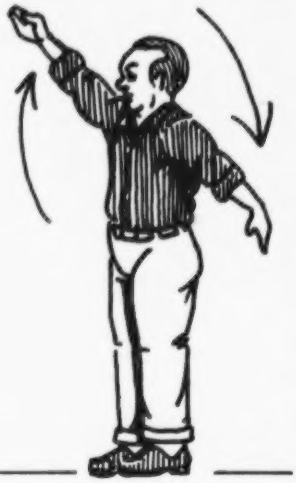


- Knee raises. Stand with feet together and arms at side. Raise left knee as high as possible, grasping under the upper raised leg with hands. Lower leg to ground and repeat with right leg.

- Side bending. Stand with feet shoulder width apart, right arm bent at the elbow and reaching over the head. Bend sideward to the left at the waist, sliding the left hand down the leg as far as possible. Repeat on other side. DO NOT BOUNCE.



- Arm circles. Stand with feet shoulder width apart, arms at side. Make large circles with arms in a windmill fashion—one arm follows the other. Move forward with both arms, then backwards.



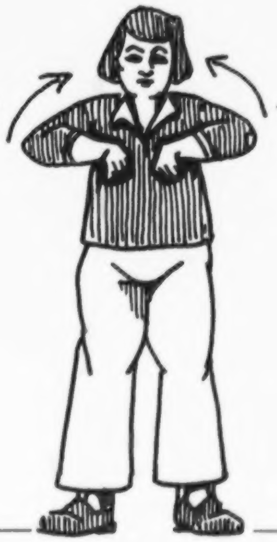
Flexibility (Stretching) Exercise Program

Frequency: 2 to 3 times a week.

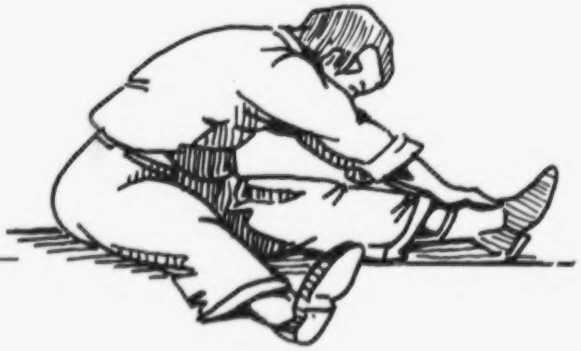
Intensity: Hold each exercise position for 5 seconds, until you feel a slight pull. DO NOT BOUNCE.

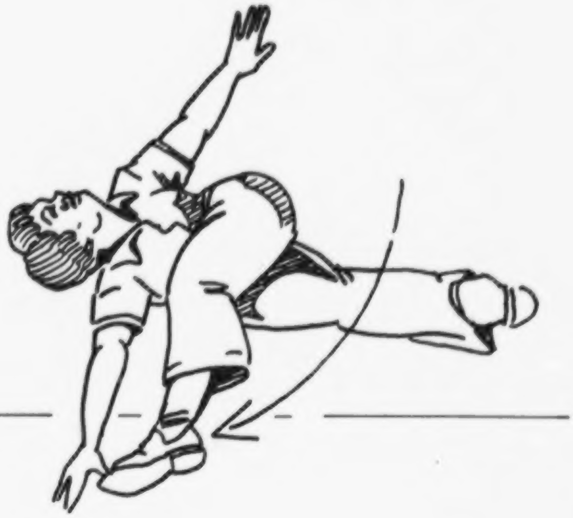
Time: Do each exercise 5 times. REST. Repeat it 5 more times.

- Shoulder and chest swing. Make a fist with both hands and place together, shoulder height. With elbows high, move both fists backwards as far as possible. Bring them back together again. Do Slowly.



- "V" sit. Sit on floor with your legs spread comfortably apart. Reach for your right foot with both hands, grasp any part of your leg you can reach and hold for 5 seconds. Repeat for left side. DO NOT BOUNCE, PULL SLOWLY FOR 5 seconds.





- Leg, hip, and back stretch. Lie on your back with your feet together and arms out straight from your shoulders. Lift your right leg up and over your left, trying to touch your left (opposite) hand. Repeat with the other leg. Try to keep shoulders flat on the floor. Twist at waist.

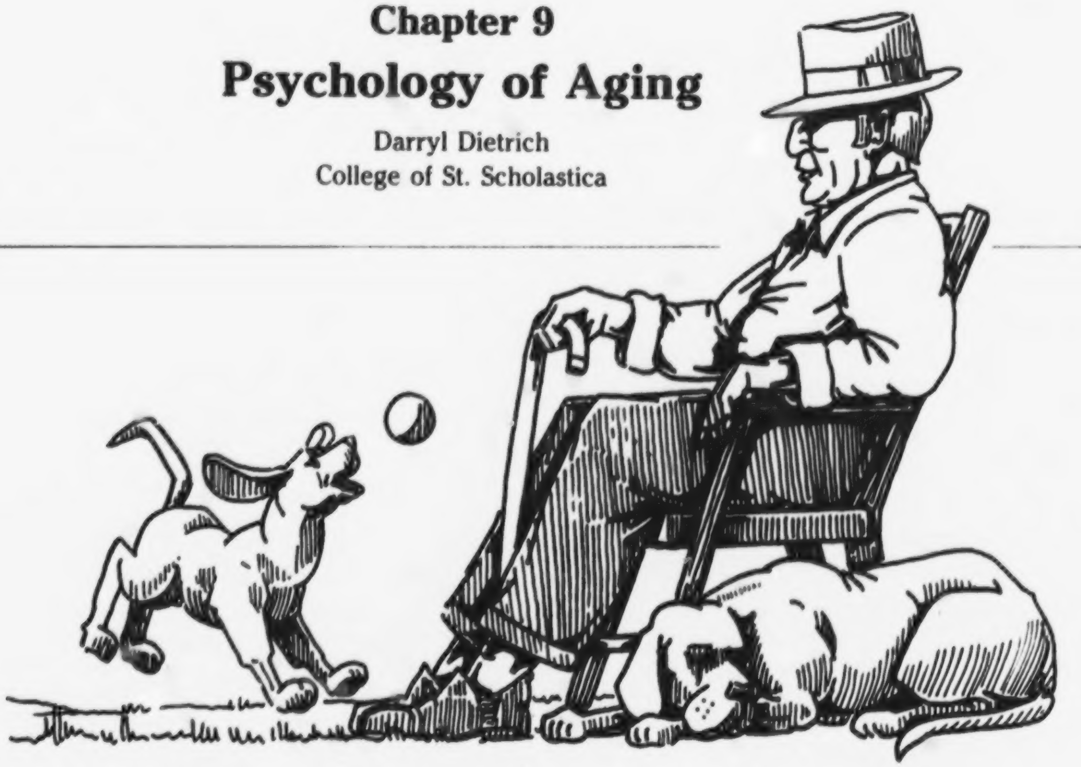
Summary

Regular physical activity is vital—for you, as well as for your older relative or friend. Exercise or participation in an activity can reduce stress, keep you healthy, make you feel better about yourself, and give you more energy for your daily tasks. It is well worth your time to set aside 15 to 30 minutes, 2 to 3 times a week for exercise...for fitness!

Chapter 9

Psychology of Aging

Darryl Dietrich
College of St. Scholastica



What Is Psychology?

When you see or hear the word "psychology" what do you think of? Just what is psychology, and what do psychologists do? In answering these questions, many people think about "mental problems" or "mental illness"—and they are partly right. But the things that psychologists study and do are not limited just to serious mental problems. This chapter, therefore, will not only help you understand the mental problems or difficulties experienced by some older adults, but it will also explain many of the normal psychological processes that are experienced by most older adults. The information presented in the chapter can help you work more effectively with the older adult for whom you are caring by giving you a better understanding of his or her feelings and behaviors.

It is also hoped that a better understanding of the psychology of aging will help you in deciding whether to seek the assistance of **mental health professionals,** such as psychologists, psychiatrists, social workers, and counselors. You should be aware, however, that if a person is not familiar with the mental health professions, he might resist seeking their services because he doesn't realize what assistance they can provide or because of embarrassment at being considered a "failure at life" or being considered "crazy."

CONTACTING A MENTAL HEALTH PROFESSIONAL

If you don't know what mental health professionals do or if you feel that you don't even know what to ask them, keep in mind that they are accustomed to explaining the services they provide. For example, psychologists are ethically and legally bound to maintain confidentiality and to provide you information on their specialty skills, procedures, and fees before you make the decision to use their expertise. They can also give you suggestions for getting someone, such as the person you are caring for, to seek their help. To contact a mental health professional, ask a physician for a referral or look in the Yellow Pages of the telephone book under Mental Health Services.

Changes and Losses

As a starting point for understanding the psychology of aging, it is helpful to "put yourself into the shoes" of the older person for whom you are caring. In this section we will try to see things from the point of view of older people by taking a look at some of the changes and losses many of them have experienced. This is important to do, because changes in a person's actual or perceived situation can strongly affect her feelings of self-worth, her general happiness, or the decisions she makes. This is sometimes hard for younger relatives and friends to appreciate if they have not had the opportunity to think about it.

While change occurs throughout life, the typical older person experiences different kinds of change. As described in the next box, many of these changes are perceived as losses.

CHANGES AND LOSSES

Social roles. Changes in social roles can be perceived as losses. Examples: (a) Retirement can involve loss of prestige and self-esteem or even a sense of purpose. (b) When adult children become caregivers to their elderly parent, the parent may perceive a loss of independence and control or a loss of self-esteem. (c) Widows and widowers often experience loss of social roles because people do not know how to relate to them without their spouses.

Biological changes. Normal biological changes (covered in Chapter 6 on *Changes in the Body*) can cause younger adults to hold a negative view of aging or can even cause older persons themselves to view old age in a negative way. People might overestimate the impact of these physical changes, and they sometimes think of old people as less capable than they really are just because they "look old." This can hurt the self-esteem of the older person, or it can lead to the over-supportive environments discussed in the next section.

Death/Disablement. Death or disablement of loved ones and friends involves loss of important sources of support and enrichment. As she looked around her living room, one widow eloquently expressed this loss by saying, "I miss him in every corner." It is not just the sadness and emptiness experienced by the bereaved, but also the loss of emotional support and mental stimulation that may have a negative impact.

Time. Most of us have noticed that time seems to pass more rapidly as we grow older. For some people, this is seen as a loss of time, of opportunity, of youth, etc.

The point in discussing these losses is not to paint a gloomy picture of old age. These losses do not occur for everyone or are not perceived as losses by everyone. In fact, from having lived for many years, people also gain wisdom, insight, broader perspective, and the freedom to do new things.

DOES PERSONALITY CHANGE IN OLD AGE?

Some people say that certain behaviors and attitudes they see in old people, like "being cantankerous, overly cautious and fearful, overly dependent, self-centered," and so on, are due to "old age." But people do not usually change just because they have grown old. In fact, as a general rule, you can expect both the positive and negative behaviors you have seen in a person all through his adult life continue into his old age.

Therapeutic Environments

One of the goals you should have in mind in caring for an older person who has experienced losses is to try to design the physical and social environment so that it neither overwhelms nor over-supports the person. Try to have the environment slightly challenge the individual by taking into account the match or mismatch between the demands of the environment and the individual's physical, mental, and emotional characteristics.

Because most of us want to help others, there is actually the danger of doing too much for the older person in our care. If, instead, we encourage as much independence and self-responsibility as is possible while not being neglectful, we can actually help the individual function at a higher level for a longer period. This is called "providing a therapeutic environment." As discussed in the next box, there are several ways in which therapeutic environments can be beneficial.

THE BENEFITS OF THERAPEUTIC ENVIRONMENTS

A **PHYSICALLY** therapeutic environment can help maintain a person's health through exercise, stress-reducing activities, and good nutrition. Even if the individual has physical or sensory limitations, you can help the older person learn new ways of doing things to adapt to these limitations. Your physician can direct you to rehabilitation specialists, such as occupational therapists, who can help you.

A **MENTALLY** therapeutic environment can help keep a person's mental abilities sharp through stimulation and use of the mind. Encourage her to read, or read to her if she has sight problems. Help her to have friends visit or to go visiting. Encourage her to participate in family activities, community events, and creative projects. Let her do as much of her own "mental" work as possible, such as keeping a checkbook and arranging appointments.

A **MOTIVATIONALLY** therapeutic environment can improve self-esteem by encouraging independence and feelings of competence. In addition to the physical and mental benefits of doing the tasks discussed above, the individual is also more likely to have feelings of being in control.

In overly supportive environments, other people make decisions for the older person that she could be making for herself. It has been shown that such situations not only demoralize a person but also fail to promote growth and can lead to serious problems such as "learned helplessness." This can happen when individuals no longer believe they have control over their own lives, so they become dependent and unwilling to take the initiative in doing things for themselves. The opposite could also occur, in which the person attempts to maintain a sense of control by resisting your help and suggestions. Recommendations for dealing with such problems are discussed in Chapter 2 on *Being a Caregiver* and Chapter 4 on *Communication in the Family*.

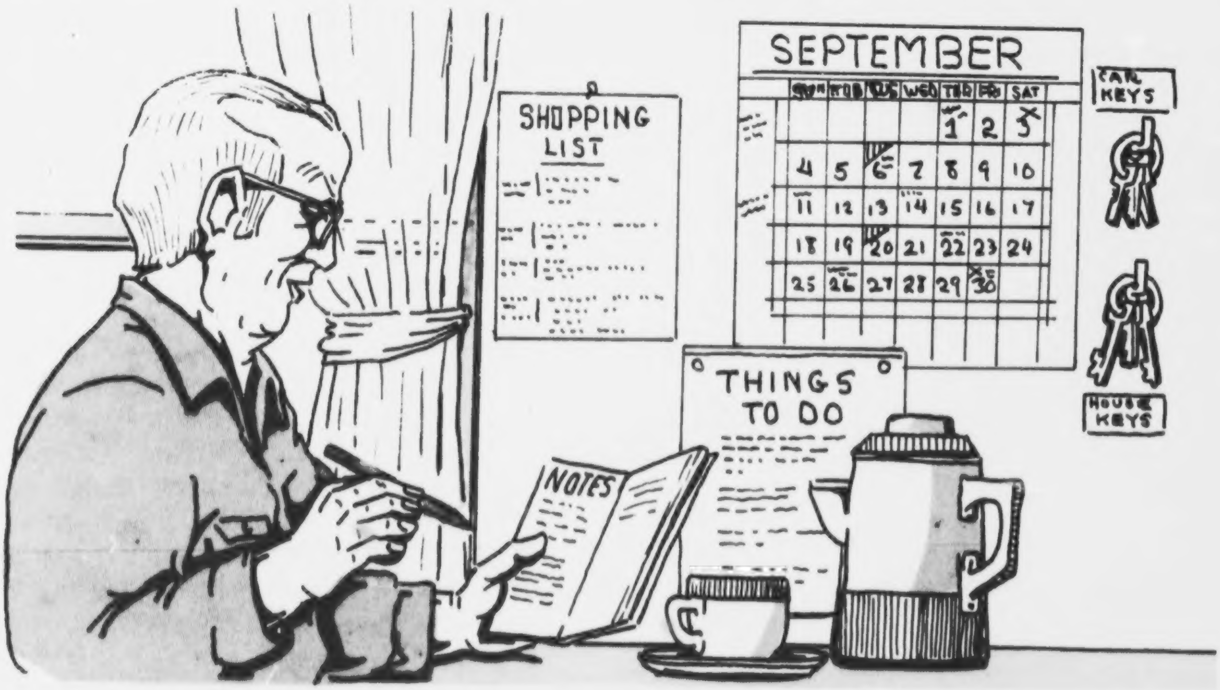
Also keep in mind, as mentioned earlier, that actual losses are not severe for everyone and that there are important gains from having lived many years. Caregivers often mention that their older relatives seem to be saying: "If you need me I am still here for you. I have learned a lot in my many years of life. Maybe I can help." Whether the older person actually says this or not, remember that he does have a store of knowledge, skills, judgment, and wisdom that can be tapped. Taking advantage of these resources amounts to providing a therapeutic environment which can benefit the individual by changing his feelings of loss to feelings of self-esteem, competence, and usefulness. As discussed in Chapter 4, participating in the person's life review (or reminiscence) can also be therapeutic.

Memory

In this section we will focus on the mental ability that older people most often worry about: memory. Although there are some normal changes in memory as people grow very old, most people do not experience the severe kinds of memory loss discussed in the next section on dementia. Thus, for most elderly individuals the greatest "memory" problem is not actual memory decline but rather the fear of memory loss and mental decline.

This emotional aspect is so worrisome and fits in so well with myths about old age, that many older adults find it difficult to even discuss the issue. Keep in mind, therefore, that it might be necessary to help the older person overcome his embarrassment or reluctance to discuss memory before you can teach him the memory improvement strategies discussed in the Memory Tips box. Much of the memory "loss" is a perceived loss due to expectations that memory will be getting worse. You can think of examples of poor memory in younger adults too, but when they forget no one makes a big deal about it. When an older person has a lapse of memory, however, you often hear her say things like, "I must be getting old," or "I hope I'm not getting senile." You can help by not making such statements yourself! You could also explain to persons who say such things what you've learned about memory and aging in this chapter.

There are many things that can be done to maintain good memory well into old age. Much of the so-called poor memory in adults of all ages is simply due to indifference or lack of attention to the information to be remembered. Sometimes we forget information because it really wasn't important enough to remember. If the information is considered important, use the techniques explained in the box entitled Memory Tips.



MEMORY TIPS

Pay attention. Repeat the to-be-remembered information to yourself or to another person. Concentrate on the information. For example, say the person's name out loud or to yourself when you are introduced: "It's nice to meet you, **Darryl.**" When you park your car, look around to familiarize yourself with its location.

Use "external aids." Do not rely on your memory in the first place, even if you are young. Instead, (a) take notes (keep a notebook handy in purse or pocket), (b) keep a calendar-book schedule, and (c) keep a "to do" list. Keep things organized in their usual places around your house. Put your keys down in the same place every time. Write down the location of your car when you park it.

Memory strategies. To put things even more firmly into your memory, use one or more of the following strategies:

- **Categorize information.** For example, a shopping list that has all the vegetables together, followed by the meats, then the toiletries, etc. This can help if you forget to take your list along to the store.
- **Visualize images.** Picture in your mind what you want to remember. In trying to remember a name, make an unusual association with an outstanding physical feature you'd be likely to notice the next time you see the person. For example, say to yourself, "Dietrich should be diet rich" if you notice that he is overweight.
- **Visualize locations.** Place a list of items you want to remember in order around a mental image of a familiar room in your house. You can then mentally go from location to location within the room when you want to recall the list. This is useful when making speeches.

Utilize cues for recall. Many times the information "is in there" but you cannot seem to get it back out of your memory. If you have used good memory strategies like those discussed above, try visualizing in your mind what you did in learning the information in the first place. Even if you did not use one of those methods, the very simple technique of going through the **alphabet** while visualizing the person whose name you are trying to remember can result in your recalling the name.

Whatever method of recall you use, the key is to **not give up too soon**.

The techniques listed in the Memory Tips box can greatly improve memory for important information in most individuals. But what about people with severe memory impairment? Such problems, with their resulting memory and behavior changes, will be discussed next.

Dementia

The terms "dementia" or "organic brain disorder" refer to disruption of normal thinking and/or memory processes. Because the word "senile" means "typical of old age," the most common type of dementia in old people is called "senile dementia." Many people mistakenly shorten this term and use the word "senile" alone to refer to such problems. You have probably heard people make comments like this when they have a memory lapse: "I must be getting senile." Statements like that tell us that many older adults do worry about dementia. The purpose for this section is to help reduce these worries by pointing out that dementia is not typical of old age and to provide information about dementia so that if it occurs in your family you will better understand what is happening and how to get assistance.

There are two major types of dementia (or organic brain disorder) that occur in old people: (a) **senile dementia**, often called Alzheimer's disease (and technically called primary degenerative dementia), and (b) **multi-infarct dementia**, which used to be called cerebral arteriosclerosis or hardening of the arteries, and which is caused by a series of small strokes over time. Together, these two account for most (about 80%) of the organic brain disorders in old people. But it is important to keep in mind that only about 5% of old people have significant organic brain disorders, with such disorders being rare under age 60 and rising to about 20% of people over age 80. Because it is the most common organic brain disorder, we will focus on Alzheimer's disease in the rest of this section, but the general symptoms and recommendations for multi-infarct dementia are similar.

The symptoms of Alzheimer's disease include loss of intellectual abilities and memory impairment to the extent that social or occupational functioning is interfered with. Although research is pointing toward several promising explanations of what causes Alzheimer's disease, there is at this time no cure. Therefore, mental health professionals focus on managing the behavior problems that result from someone not being able to think well or remember. Mace and Rabins' book, *The 36-Hour Day*, is a sensitive and practical source of advice.

Because these general symptoms can be caused by many other factors, a diagnosis of senile dementia by mental health professionals also involves several other criteria. Whatever the actual cause, if you notice intellectual or memory changes in someone, you should ask the older person's physician to arrange for a consultation with a specialist in order to determine what the problem is and how it can be managed. This specialist could be a psychiatrist, neurologist, geriatrician, or internist. The key is that he/she **knows about aging and dementia.**

Even if Alzheimer's disease is the most likely diagnosis, your physician or the consulting specialists can direct you to mental health professionals who can assist you in several ways. They can:

- teach you how to manage the person at home during the early stages of the disease, including the use of memory aids like those discussed above and in Chapter 7 on *Nutritional Needs.*
- help you locate other resources, such as those described in Chapter 12 on *Where to Get Help*, as the older person becomes too difficult to maintain in the home.
- counsel you as you attempt to cope with what has been called "the thirty-six hour day" and "the long good-bye."
- direct you to the Alzheimer's support groups that exist in many communities.

Furthermore, by consulting your physician, you might find that the mental disorders are caused by something that can be treated, such as depression (see the next section), medications, malnutrition, infection, etc.

Depression

Depression is the most common mental disorder of old age. The psychological symptoms of depression include: sadness, apathy (lack of interest in most everything), inactivity, a negative self-concept, and a pessimistic outlook. Depression often expresses itself with physical complaints, loss of appetite, severe fatigue, sleep disturbances, constipation or diarrhea, etc.

On the surface, depression can look much like dementia. The depressed person may start exhibiting behaviors that look like dementia (this is called "pseudodementia"), such as starting to forget things or complaining about poor memory or concentration, and she could then be misdiagnosed as having Alzheimer's disease. Because depression is curable through various means (discussed below), it is very important to determine which illness the person has. There are several ways of telling the difference between the two. See the following box for important differences.

DEPRESSION	DEMENTIA
Symptoms usually develop over a period of days or weeks or may be sudden, such as when associated with psychological stress.	The onset of dementia, such as Alzheimer's disease, is usually slow.
Symptoms appear before intellectual decline.	Intellectual decline appears before depressed mood appears.
Onset of depression is often associated with severe stress or loss, like the death of a spouse or loss of a job. Might also be related to chemical disturbance in the nervous system.	Senile dementia does not have a stressor as its cause. Dementia progresses in the brain no matter what events occur in the person's environment.
Complaining about memory problems, the state of the world, or poor health is typical. Depression often is disguised in physical symptoms that don't seem to have any obvious cause.	Instead of complaining, senile dementia patients tend to understate, deny, or conceal their problem.

Most depression is treated by antidepressant medications or psychotherapy, although in a few very severe cases electroshock therapy may be used after all else has failed. Ask your physician, psychiatrist, or psychologist to explain her choice of treatment. The important thing for you to do is to be alert for signs of depression and seek help. Depression is usually curable.

An extremely critical reason for being alert to signs of depression is that depression is the most common cause of suicide. People often "signal" their intention to commit suicide by the things they say or do, but you have to listen carefully to notice these signs. Although the majority of depressed people do not attempt suicide, suicide signals and threats must be taken seriously. If you suspect that someone is thinking about suicide, do not hesitate to get professional help. Many communities have "suicide hotlines" or "suicide prevention centers." See the Yellow Pages of the telephone directory under Mental Health Services or Crisis Intervention Service.

Dying and Bereavement

An important, yet difficult, issue is dealing with death. People find it hard to talk about death or to talk with a dying person. But talking usually helps! The psychological aspects of dying discussed in this section can help you understand your reactions and those of the dying person.

Kübler-Ross, in her book, *On Death and Dying*, discusses emotions that people go through as they attempt to deal with the knowledge that they are dying. These emotions are described in the next box. Knowing that these emotions are normal can help you better understand and interact with the dying person. In fact, if you are grieving the loss of a loved one, these descriptions can also apply to the emotions you are experiencing. It is important to note that the emotions people display in reaction to all sorts of major losses (such as burning of a house, losing a job, or becoming disabled) are similar to Kubler-Ross's descriptions about dying.

REACTIONS TO DEATH AND DYING

Denial and Isolation. First reactions include: "No, not me!" "It must be a mistake." Sometimes the person seeks out other doctors for third (fourth, fifth) opinions, or he goes to faith healers, or he denies that anything is wrong. This denial can be a healthy buffer against the shock of learning that you probably are dying or that someone has died, allowing you time to develop more rational coping behaviors.

Anger. "Why me!" is a typical reaction. Anger, envy, or resentment may be directed at anyone around the dying/bereaving individual. The key is to understand the great sense of loss the person is experiencing and neither to take his comments personally nor to avoid him. Things will be said that you must not let interfere with your love and concern for the person.

Bargaining. Sometimes when anger cools down somewhat, there are brief periods in which the person seems to want to make deals to delay the death. The deals might be with God, medical staff, or with the illness itself. For example, the person might ask to be allowed to live just long enough for her son's graduation from college...then his wedding...then her grandchild's birth...

Depression. Two types of depression result from the great sense of loss due to the imminent death. **Preparatory depression** or anticipatory depression is aimed at "preparing" for separation from the world. The person must be allowed to express his sorrows in order to make final acceptance easier. **Reactive depression**, which is in "reaction" to past losses, perhaps with guilt or shame, might require support for his self-esteem.

Acceptance. Eventually, a dying person might reflect upon his coming end with quiet expectation. At this point he will most likely be tired and quite weak. Although he might be less responsive to conversation, or you might be uncomfortable, **don't stay away.** Short visits, even if in silence or only holding hands, can be very important to the dying person. These visits will almost certainly help you, the bereaved, work through your grief.

An important point to remember is that each person is different. We should focus on individual needs and desires to help people cope with their dying or grief in the way that is most appropriate for them. For example, allow openings in conversations that will permit them to bring up topics (such as their dying) as they wish, without forcing such topics on them "in order to be sure they go through all the stages."

Viewings, wakes, memorial services, and funerals can be beneficial for the bereaved. Most cultures have developed rituals that in addition to honoring the dead, also provide support that helps the living to adjust to the loss. Generally we should attend these rituals, if only for our own benefit. The rituals provide a sense of closure that can make adjusting to the loss easier.

The stress caused through the loss of a spouse or close relative can be health-and life-threatening (see Chapter 3 on *Managing Stress Effectively* for further discussion). This loss is more stressful for men, who die at a greater rate than women during their bereavement. Although there is no "right" amount of time for the period of deepest bereavement, you can expect the first year after the death to be especially hard because of the series of anniversaries, birthdays, and holidays that will occur for the first time without the deceased individual.

The most important thing that you can do for the bereaved is to keep in touch, such as in telephone calls, brief visits, and social invitations. The bereaved usually want to talk about their deceased loved ones, and you need to make the effort not to display excessive discomfort or cut off this line of conversation. And, keep in mind that many bereaved individuals resent being told that you understand how they feel or that it will get easier. Many communities have support groups or programs for assisting widows and widowers through their most difficult times. To find out about such programs, contact the sources described in Chapter 12 on *Where to Get Help*.

Summary

The "psychology of aging" includes a wide variety of topics about the perceptions, feelings, and intellectual characteristics that are common in older adults. It also includes mental disorders, such as dementia and depression, which occur only in some older adults. Understanding the psychology of aging can help you work more effectively with your relative or friend and give you a better understanding of his or her feelings and behaviors.

Chapter 10

Living Arrangements

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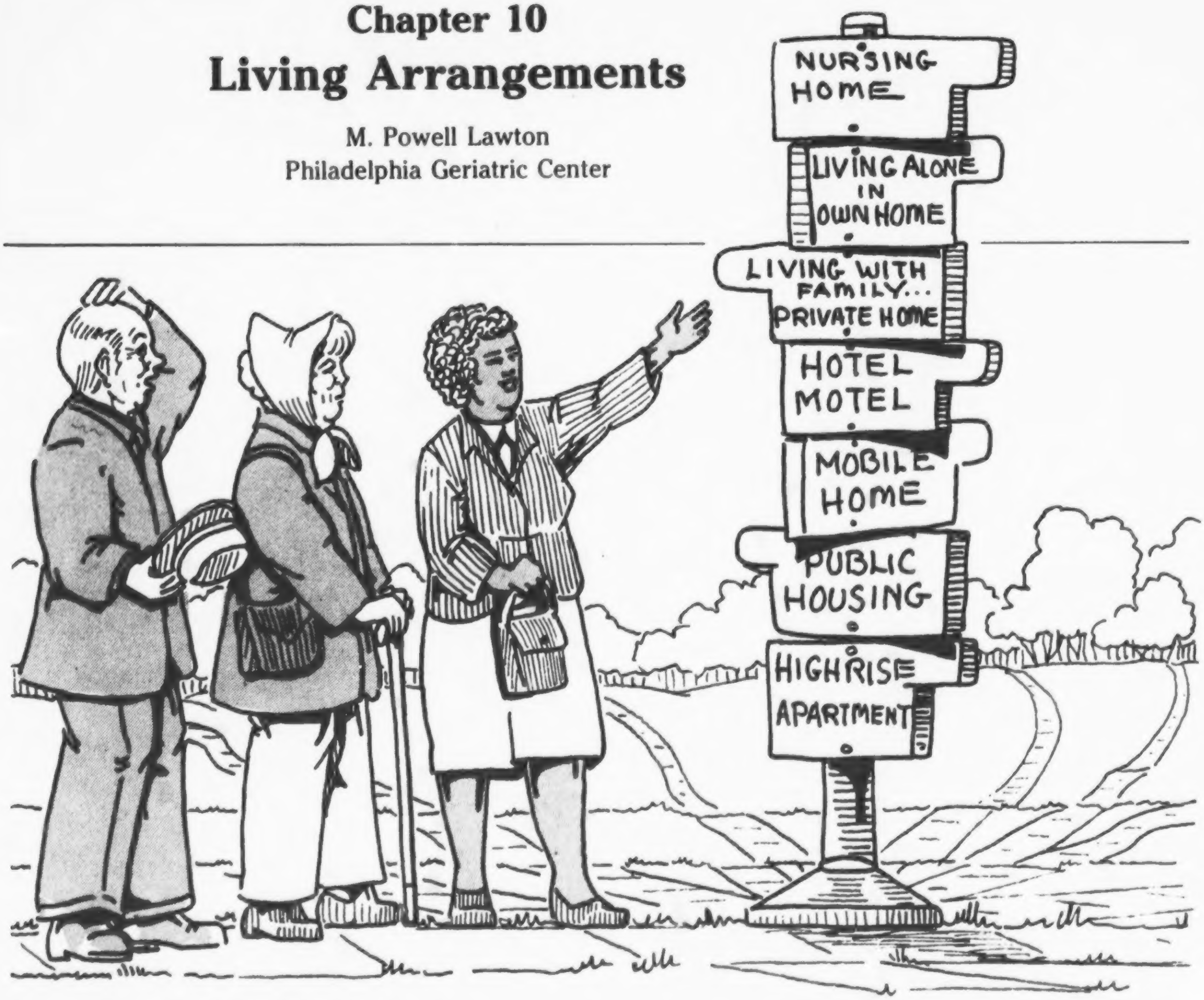

Some Typical Living Situations

The following three people are very different. It appears that each one might need a new kind of living arrangement, but is a change the best idea? Ask yourself this question as you read about the three of them.

- **Norma is a widow living alone, who sometimes needs help from her daughter-in-law with shopping, some extra home cleaning, or a check of her medicine supply. While she needs occasional help, she prefers to continue living in her familiar surroundings. She likes her neighborhood, where she has a number of friends with whom she has shared over the years all the joys and sorrows of marriage, children, career decisions, family funerals, and weddings. Thus, for her the home represents not only physical possessions but also security, life history, and fond memories.**
- **Helen is physically healthy, but very confused. She can't remember the proper order in which to put on her clothes. She forgets which meals she has taken. She tends to wander, and sometimes goes about the neighborhood and has to be brought back by a neighbor. Her daughter lives with her and looks after her mother's safety.**
- **John retired from a nearby paper mill about five years ago. Things were going well for him until last year when he had a stroke. He is now physically disabled, has**

unclear speech, and needs assistance in dressing and bathing. However, the good part is that his mental ability is intact and his wife, Lucy, continues to be in good health. Thus, they are able to maintain the home where they have lived for the past twenty years.

In this chapter, we will examine the important features of the various types of living arrangements available for older people. The chapter provides you with information not only about the various types of housing, but also about the abilities, needs and preferences that should be considered in making decisions about living arrangements. The major questions we will address in this chapter are:

- What are the important factors to consider when making decisions about living arrangements?
- How do the needs for independence and security influence the decisions people make about their living arrangements?
- What are the various types of living arrangements available for meeting the needs of the diverse population of older people and their caregivers?
- What are the special features of each of the housing options?

This chapter cannot say what is best for everyone. What works best for someone depends upon whether or not it meets her needs. If you know something about the person's needs and preferences and about the types of living arrangements that are available, you are in an excellent position to help her make a decision.

What Everyone Needs In a Home

Do you know what your home provides you? Think about it. Sure, it keeps you dry and warm, but there is more to having a home than just keeping dry and warm.

First, all people need some place to call their own. Having a piece of our own turf gives us a place where we can sometimes do as we wish. It gives us a place to be alone in. It gives us a place to which we can invite friends. If possible, it is good to preserve this personal territory. Thus, one of the major benefits of having a place to call one's own is that it satisfies the desire for **independence.**

Besides needing an area of their own, people need a place that is safe and where basic needs can be taken care of. Thus, the second major benefit of having a home is that it satisfies the need for **security.**

Let us consider some different ways that people may live, thinking about how the desire for independence and the need for security might be satisfied in each type of housing.

Non-Institutional Living Arrangements

Living alone in your own home. Many people over age 65 live alone in their own houses, apartments, or mobile homes. Though most of them are not lonely, there are some who do not have enough contact with other people. Those who are more prone to such social isolation tend to be poor, in worse health, single or widowed, older, and without children or other relatives living nearby. Generally, it is a combination of these factors, rather than any single factor, that leads to social isolation.

Most older people who live alone see their relatives and friends very frequently. It is this informal support system that tends to encourage staying where they are, provides them with the assistance they need, and enables them to maintain their preferred lifestyles as long as they can.

Living with a relative. Less than 20 percent of older people live with relatives. Some call this separateness a symptom of the uncaring nature of middle-aged adults. Actually, the majority of older

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people do not wish to live with an adult child. Some refer to older adults' desire to live near but not with relatives "intimacy at a distance." In fact, when relatives do live together, it is often the younger people who move into the older adult's home.

Combining generations does save on household expenses, and shared households are, therefore, more prevalent among families with lower income. Another important reason for sharing a home is the poor health of the older person. There are some families who want to live together, who simply assume that it is the only thing to do, who would not consider any alternative. But this is not everyone's way.

What would living with your relative mean to you? Today we recognize much better than we did a few years ago that caregiving relatives have a right to their own lives too. A relative may be a loving caregiver, but may not be able to oversee the life of a frail adult 365 days per year. The important rule is to try to assess your own strengths and resources objectively. Deciding to have your mother move in because of guilt or a feeling of compulsion may well end up badly for both you and your mother. In making the decision, it might be helpful to answer the questions in the following box.

SHOULD THE OLDER PERSON MOVE IN WITH YOU?

____ Are relationships among the current household family members good?

____ Are there other family members (such as young children or handicapped individuals) who demand a lot of the family's care or attention?

____ Is your home convenient to places your relative would enjoy going, such as church, senior centers, or friends?

____ Will caring for this person interfere with your job or participation in other activities?

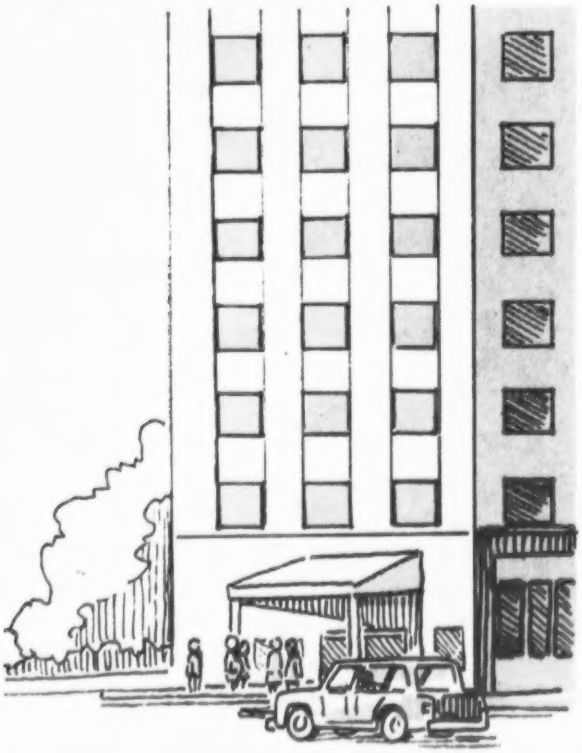
____ Can privacy for all family members be maintained in your home?

____ Is the house physically compatible with any health, sensory, or mobility problems the person has?

____ Are there financial resources for a living arrangement other than having your relative live with you?

____ Are community resources available for respite care, day care, or home health care assistance?

Senior-citizen housing. Many independent older people have moved to high-rise apartments in cities where other people their own age live. Is your relative the sort of person who would do well in such housing? It is worthwhile visiting such a place to see what life there is like. We know that most of the two million people who live in such housing went there because they wanted better housing, or more social life, or a more secure environment. We also know that for most people it is an excellent choice, a place to maintain independence while having the security of other people living nearby.



Congregate housing. Congregate housing offers some special services in addition to a good place to live. There is always a dining room where all or most tenants eat at least one meal a day. While a few low-cost (subsidized) housing projects have congregate services, such services tend to be expensive and they are more likely to be found in nonsubsidized housing. Whether your relative needs congregate housing is a question that requires a lot of thought. Congregate housing is best for people who need a moderate amount of help.

Shared housing. Sharing a house takes advantage of the fact that some older people live in large homes with extra space that they are willing to rent to another person. Sometimes the renter may be a younger person. This combination of ages can work quite well, because the younger person either does some chores for the older homeowner or provides a sense of security simply by being there. Shared housing arrangements are best initiated by an agency that matches up homeowners and renters.

Board and care. Board and care, boarding homes, and domiciliary care are names given to group quarters where meals and supervisory care are provided, but not medical or nursing care. Ideally the people who live here should not have medical problems requiring care. There are many licensed facilities where such mild care is given in high-quality environments. At times board and care homes are unlicensed and some may even accept people who are too sick or frail. This practice can put the older person at risk of physical decline if proper care is not given.

Adult foster care. Foster care is another alternative for frail older persons who prefer to remain in the community. One example of this arrangement is the Family Care Program of the Miller-Dwan Medical Center in Duluth. This program places older people in the homes of preapproved, specially trained families. Less costly than nursing homes, this alternative is especially appropriate for those who need some assistance and supervisory care, but prefer to maintain the benefits of community life.

An excellent discussion of the various types of housing arrangements included in this section can be found in a very readable book entitled *Where Can Mom Live? A Family Guide to Living Arrangements for Elderly Parents* by Carlin and Mansberg.

Although congregate housing, adult foster care, and some of the other varieties of housing can offer some supportive services in addition to a roof over the head, most of what has been described so far represents housing either for relatively independent people or for less independent people who have someone to help care for them. But, there are some individuals who require the higher levels of assistance provided by nursing homes.

Nursing Homes

The nursing home is a residence for people who cannot care adequately for themselves. Many people think of the nursing home as a typical residence for older people. Actually, only five percent of older people live in institutions, and the great majority of all people will live out their lives without ever entering a nursing home. Today few people enter a nursing home unless they have a major physical or mental condition that makes them unable to live independently.

Although the decision to place a loved one in a nursing home is often the best alternative, it is a difficult decision that is dreaded by many families. One reason for this reaction is that society has painted a dreary picture of the institutionalized nursing home resident as an aged person who is dumped in a facility by a relative who just doesn't care or want their family member anymore. This gloomy portrait has been carried over from the "poor farms" of years ago. This myth views the nursing home as a poor substitute for a loving, caring multigenerational household. Instead, the nursing home should be viewed as a protective, supportive, and rehabilitative environment which is selected as the best feasible living arrangement for a particular older person with declining physical or mental health.

Assurance of the most appropriate services for those considering nursing home care is the goal of the preadmission screening process followed in Minnesota. All applicants to nursing homes, or any older person in the community not on a nursing home waiting list, may receive preadmission screening which identifies the available services in the area so that each person can make a decision about his or her care and living arrangements based on accurate information. Another purpose is to determine the level of care and the cost for care in a nursing home. Though this service used to be available only to nursing home applicants, it is now available to anyone needing evaluation. The screening may be arranged by contacting your county Social Service Department. More information about preadmission screening is included in Chapter 12 on *Where to Get Help.*

NURSING HOME

Many of today's nursing homes provide stimulating environments with increased social activities, easy access to religious services, musicals, creative crafts, recreational groups, and rehabilitative services. The older person and family may continue or even strengthen their family ties after nursing home placement. Often times, when family members are relieved of giving daily physical care tasks, they may discover renewed strength to provide vital emotional support to their family member. Ask about the nursing home's policies and procedures regarding families—ask how they encourage the family to be involved.

Not all nursing homes give high quality care. Therefore, nursing home placement requires investigation by both the family and the person considering admission, including visits to several homes, talking with local professionals about the home, or talking with families of current residents.

In what situation would you consider nursing home placement as an appropriate choice? Why? Think about these important factors and others listed in the following box before placing a loved one in a nursing home.

SELECTING A NURSING HOME

Finances: Some facilities initially admit only private pay residents but allow them to stay with Medicaid funding once their private resources run out. Some may admit Medicaid funded residents initially, but give preference to private pay applicants on the waiting list. It's important to discuss these procedures with the nursing home your family is considering. A social worker, lawyer, or local legal services office can also be helpful, especially to discuss the spouse's assets.

It's important to know that Minnesota has a law that prohibits charging higher rates to private pay than to Medicaid patients. Refer to Chapter 11 for more information regarding financial matters.

Location: The importance of maintaining family ties in the nursing home cannot be overlooked. The facility should be within acceptable traveling distance for family members.

Staff: Visit the nursing home and observe staff caring for residents on weekdays, evenings, and weekends. Ask what the ratio of staff to residents is.

Rehabilitation services: Physical therapy, occupational therapy.

Meals: Observe the dining room routine. Ask about the variation of meals and what choices the resident makes.

Activities: Observe activities. Talk with the activity director, with residents, and with the social worker.

Family physician: Find out if your relative's personal physician will continue to care for your relative.

If you would like to read more about choosing a nursing home, we recommend Chapter 13 of a book entitled *Taking Care: Supporting Older People and Their Families* by Hooyman and Lustbader. This book is easy to read and discusses a number of topics which may be of interest to you. Another excellent book that discusses nursing homes is *The Nursing Home Dilemma* by Doug Manning.

How Does One Ever Choose Among These Possibilities?

Some decisions are easy. Many older people know exactly what they wish to do. For the great majority, what they wish to do is stay right where they are! If your relative is such a person and you disagree with her wish to stay in what looks like a bad situation, it is certainly reasonable to discuss it. However, if your relative is determined, she will pro-

bably win! Unless the decision is causing risk to health or life, it probably should be accepted. It is difficult to fully appreciate how important having one's own territory is. It would be helpful to consider how important your own home is to you, to know exactly how it is to feel as if you belong where you are. You might know that it may not always be easy to continue to live in a place that you can't clean as often as you used to, or where you hesitate before deciding to climb the stairs, or where you don't feel safe walking to the store without a companion. Yet, you are willing to endure these problems because it's your own home and you still have the freedom to do many of the things you enjoy.

As an adult child of a frail parent, should you try to persuade your mother or father to move in with you? We do know that as a person's health declines they become more willing to accept a loss of privacy or territory. In good health they might angrily reject any such offer. But if they become less independent, a discussion about such a move would be worthwhile.

Looking For A New Place To Live

Few people over 65 move to a new living arrangement, but the number is increasing slightly each year as more people over 65 have greater financial independence. If your relative is thinking of doing so, whether he wants to stay in the neighborhood or move to Florida, get in touch with others who have made such a move recently. They have dealt with the same problems and will have a similar perspective.

Sometimes the right kind of housing is hard to find. Most areas have an office for the aging (often called the "Area Agency on Aging") which is a good place to begin your inquiry. Look in the telephone directory under "Aging." If that office doesn't have information on senior- citizen apartments, home repairs, or shared housing, they will know where you can get such information.

The best final word on deciding where to live is that every family is different and must find its own solution. Finding that solution requires, first, an atmosphere of free discussion, where the members accept the necessity of learning how one another feels. Second, the best solutions eventually will have to come by accepting the wishes of the individual.

Summary

We have emphasized that in making the decision about living arrangements, one must consider many factors. First, the older person, if mentally able, must be fully involved by taking into account his or her desire for independence and security needs. Also, both of you need to be aware of the different types of living arrangements that might be good alternatives in light of your own needs and resources. Working together you can make a decision that will be acceptable for both of you!

Chapter 11

Legal and Financial Matters

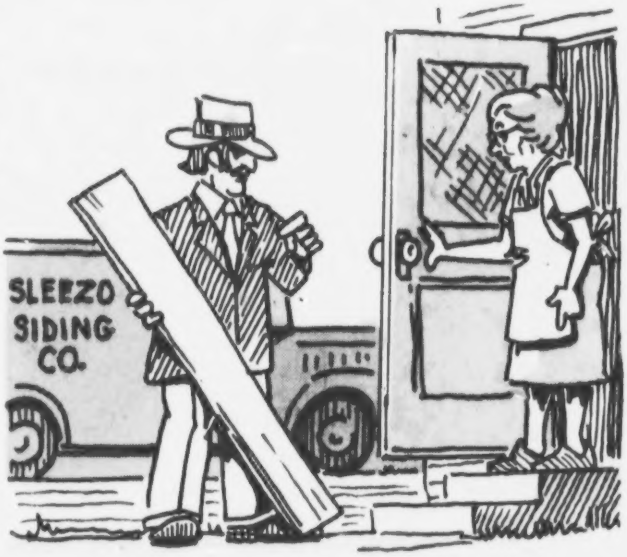
Dale Lucas
Legal Aid Service of Northeastern Minnesota

The Purpose of the Chapter

Older adults and their caregivers have many of the same legal problems as others, but they also have specific areas of concern that particularly apply to them. For instance:

- Older adults are extremely concerned about paying for **health care costs** and often are confused as how to deal with the large government bureaucracies which administer programs designed to help pay for those costs.
- Older adults also may be particularly susceptible to **consumer rip-offs,** especially from people who solicit their business door-to-door such as insurance agents, home repair contractors, vacuum cleaner salespersons, and magazine salespersons. (See Chapter 12 for additional information.)
- Another area of concern for older adults is the whole question of **passing on property.** Many believe that they absolutely must have a will or the state will take their property upon death. In some cases people are so fearful of probate costs that they transfer their property before they die. For some individuals this may be a good decision, but in some cases there may be disadvantages. Proper legal advice is essential before making any major decisions such as transferring ownership of your home.

This chapter will discuss concerns like those listed above and *general* information to prepare you in obtaining specific information that would apply to your unique situation. The chapter is *not*, however, a substitute for expert advice from a lawyer.



LEGAL
AID
SERVICE

SEEKING LEGAL ADVICE

Some people may be reluctant to seek legal counsel because of their suspicions about lawyers, their fear of high legal costs, or simply because they have not had previous opportunities to work with lawyers. They may not know that there are special legal projects designed for older adults which are not necessarily restricted for people in a low income bracket. Some law offices can be fairly flexible in the type of legal work that can be performed for older adults and are a good starting point for those who feel they may have legal problems. If you are 60 years of age or older and want advice or help on a legal problem, contact your local **Legal Aid office.**

Health Care Costs

A major concern of elderly people, who are at a higher risk of incurring substantial health care bills, is how to pay for the cost of health care. The terms Medicare and Medicaid sound alike, but are vastly different in their application. **Medicare** is a national health insurance program which applies to people who qualify for Social Security upon reaching the age of 65, or for those qualified individuals who are disabled and who are under the age of 65. Because it is in essence an insurance program, it presently applies regardless of income or assets. **Medicaid** (now often called **Medical Assistance**), on the other hand, is a program for those in need, and eligibility is based upon having low income and having few assets.

Medicare. If you are already on Medicare, you know that it does not pay for all costs of care. It's estimated that Medicare covers from 50 to 60 percent of medical costs for seniors. Because of this fact, many have resorted to **Medicare Supplemental Insurance,** commonly referred to as **Medigap Insurance.** Because of abuse and overselling of these insurance policies, most states have enacted laws to strictly regulate the sale of these policies. Minnesota, for instance, requires Medigap Insurance to be rated 1+, 1, 2, or 3, depending upon the level of coverage. It is also illegal for salespeople to sell duplicate Medigap coverage, and there must be a 30-day cancellation period from the date of delivery of the policy.

Medical Assistance. Medical Assistance, which is also called **Medicaid**, is a government program for elderly or disabled persons who are unable, because of low income and few assets, to pay for the costs of their health care. If a person is not financially eligible for Medical Assistance initially, she can become eligible by spending down monthly income or assets to the point where the eligibility level is reached. Medical Assistance is often the last resort for people who have had catastrophic medical costs or require long-term nursing home care. Over 60 percent of persons in long-term care are on Medical Assistance, because the high costs of care have forced them to deplete their income and assets to the point where eligibility occurs.

People often seek legal advice to determine what assets and income can be retained while still being eligible for Medical Assistance. Common questions that we receive in the Seniors' Law Project (at the Legal Aid Service of Northeastern Minnesota) are: "If my husband, who has Alzheimer's disease, must go into a nursing home, will we lose our home?" "We have managed to accumulate a small amount of liquid assets for our retirement; will these all be lost?" "Is there any way we can plan to help us retain the maximum amount of assets while still applying for Medical Assistance?" Legal aid offices have attorneys and pamphlets which will help you answer such questions. Also see the discussion on nursing homes near the end of this chapter.

Health Maintenance Organizations (HMO). HMO's are relatively recent developments in the health care field designed to be an alternative to insurance programs. Instead of charging a fee for each service, an HMO gives care to persons who have paid a fixed monthly charge collected in advance, plus a small co-payment for some services. HMO members no longer have to worry about payment of Medicare deductibles and co-payments or about doing the paperwork that is required with Medicare and Medigap Insurance policies. A disadvantage, however, may be that you cannot use a physician or hospital that does not have a contract with the HMO in which you enrolled unless you are referred or you have an emergency out of the HMO service area.

Each of the programs described above could require the need for legal advice. For instance, there is an appeal process for any adverse decision, and you can be represented by an attorney during any stage of the process. You may need legal advice for such things as how and when to cancel your insurance policy, how to file a grievance with an HMO, and how to make a Medicare appeal.

Sources of Income

Social Security is a federal program for retired or disabled persons who have paid Social Security Taxes (F.I.C.A.). Under certain circumstances it will also provide coverage for family members of workers. There are several types of benefits under the auspices of the Social Security Administration. Some of the benefit plans are: retirement benefits, auxiliary benefits, survivor's benefits, disability benefits, and a lump sum death benefit.

Supplemental Security Income (SSI) is another financial assistance program designed for individuals with an extremely low income. It is also administered by the Social Security Administration. Anyone who receives a total income of less than $350.00 per month and is disabled, or is 65 or older, should apply for SSI at the local Social Security office. Past work is not a requirement for SSI.

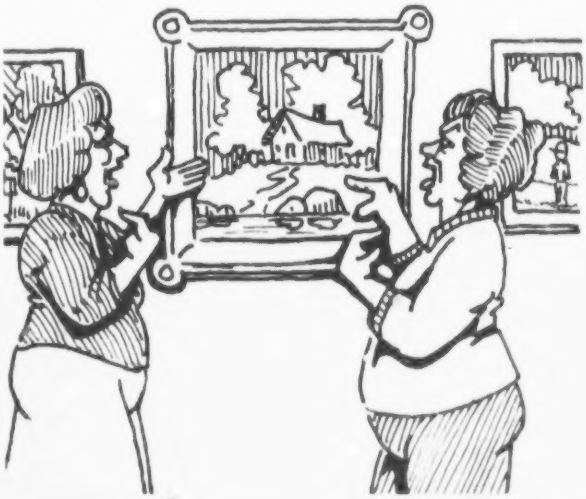
Veterans benefits and other pensions are additional potential sources of income. You may obtain more information about them by reading the booklets suggested in the summary of this chapter or by contacting your local legal aid office.

Legal Issues/ Managing Your Personal Affairs

Wills and probate. Some of the major concerns of senior citizens are about wills and probate. "Do I need a will?" "How can I avoid probate?" They are surprised to learn that not everyone needs a will, and probate is not always something which should be avoided.

If a person does not have a will, there are laws in each state called laws of **intestate succession** which provide for the passing of property upon the death of the individual. If you die without a will, your property will be passed in equal shares to your "next of kin." If you have a spouse that survives you, for instance, most if not all of your property will go to your spouse. If you have children who survive you but no spouse, your property will be divided in equal shares among your children unless you have a will. If you have neither spouse nor children or grandchildren who survive you, your property will pass in equal shares to your next of kin as they are defined by the laws of the state. If you do not have a will, the state will only take your property if you do not have blood relatives who come forward to make a claim.

Those who need a will include people who want to give **specific bequests** of property—such as family heirlooms, paintings, jewelry, coins, picture albums—to specific individuals, rather than having their next of kin take their property in equal shares. Also it would be a good idea for people with **second marriages** to consider having wills to preserve the property derived from their former marriage for their previous family. For persons with **substantial estates,** it is always a good idea to go to a professional for advice about estate planning for purposes of preserving as much of the estate as possible, and to ensure that it goes to the people you have designated.



People often ask, "How do I avoid **probate** ?" The simple answer is to give away all your property before you die. Under the laws of Minnesota, for instance, if you have $5,000 or less in your own name and do not own any real estate individually, your heirs can avoid probate. Often people with rather large estates fall into this category because they have placed their property into joint ownership, or have "life estates" and have designated "payable upon death" beneficiaries for their bank accounts and savings certificates. Surviving joint owners automatically take full ownership of the property upon the other joint owner's death. It does not pass into the estate for probate purposes. Similarly, beneficiaries of insurance policies or people designated to be paid upon death take the money automatically without having to go through probate.

Probate is not something which should be avoided in every case, however. For instance, sometimes there are favorable capital gains tax consequences from passing real estate through a probate process rather than establishing joint ownership or a life estate. There also are other pitfalls that can be encountered when property is shared or given away prior to death. It is best to transfer property only after seeking the advice of an attorney.

Another question often asked is, "Is my will valid?" In Minnesota a will is valid if it is properly signed by a competent person (called the testator) in front of two witnesses, who must in turn sign in front of the testator. All of the signatures may be notarized, but this is not a formal requirement. **Form wills** should be used only with caution and with the knowledge that mistakes can be made which may invalidate the will.

Joint ownership. There are ways of planning ahead for disability, and there are legal devices that can be used when a person becomes incapacitated to the point at which he or she cannot take care of his own affairs. Perhaps the simplest method for permitting someone else to share a person's financial responsibilities is to set up a joint checking account. Income can be automatically deposited into the checking account, and the joint owner can write checks (if it is an "or" account) to pay bills and financial obligations. Setting up such an account is not without risks, however, because the joint owner has the authority to withdraw all of the money in the account without the express permission of the original owner. The joint owner also has a **right of survivorship**, which means that upon the death of the original owner, the balance of the account will automatically go to the joint owner.

Power of attorney. A "power of attorney" is a legal device which is often used to designate legal authority to another person. A power of attorney is simply a piece of paper signed in front of a notary public which designates certain powers to the **attorney-in-fact**. It can designate specific authority or it can be very broad in scope. A power of attorney normally is revoked automatically upon the death or incompetence of the person giving the power. A "durable" power of attorney, however, is not revoked upon the mental incapacity or incompetence of the person giving the power. For this reason, a durable power of attorney can be used to plan ahead for mental disability. A caution must be provided to those giving a power of attorney, because the powers can be broad and sweeping in nature and there is always the possibility that the attorney-in-fact will abuse the power given and use it in ways that are not in the best interest of the person who gives the authority.

Conservatorships and Guardianships. For those who are incapacitated to the extent that they no longer can make rational decisions regarding their finances or personal needs or both, a conservatorship or a guardianship might be considered. These proceedings must be done in a court and, therefore, can involve the expense of hiring an attorney. They also involve the loss of certain rights of an individual to act on her own and, therefore, should be used only to the extent that they are absolutely needed.

Considering a Nursing Home. As mentioned earlier, a major legal and financial issue families face is, "What happens to assets if the care recipient goes to a nursing home?" It is helpful if this issue can be discussed well in advance of nursing home placement. We would like to give a straightforward answer as to how assets and legal decisions are handled for everyone, but the rules are complex, and it is too difficult to cover every situation. It is, therefore, advisable for a family or a couple faced with this situation to get legal advice. It is important for you to know that there are laws in Minnesota that permit a division of assets so that the healthy spouse can retain his or her homestead, as well as a significant portion of the couple's assets, even though one spouse is living in a nursing home and has applied for medical assistance.

Summary

For specific legal advice or representation, contact the Seniors' Law Project in your area through your local Legal Aid Office. The following free booklets are updated each year and are available through local Legal Aid Offices in Minnesota: *Filling the Medicare Gaps: Health Care Choices for Minnesota Seniors,* and *Knowing Your Rights: A Guide to Minnesota Senior Citizens' Legal Rights.* You will find these booklets helpful!

Chapter 12

Where To Get Help

Joan Wainer
Lakeshore Lutheran Home

A Caregiver in Need of Help

Many people are not aware of the various sources of help available in their community. Some of these resources are federally funded and others are provided by state or private agencies. A major purpose of this chapter is to introduce you to typical services that may be of use to you now or in the future.

Ideally, community resources should be thought about *before* a situation becomes overwhelming, because it is best to avoid having to make a decision during a time of crisis. The following story illustrates the importance of using community resources.

Rose Jenkins' mother, Eleanor, had lived independently until her stroke a year ago. After hospitalization, Eleanor moved in with Rose and her husband, who recently retired. The daily care routine became burdensome, especially at the point when her mother became incontinent of her bowel and bladder. Rose was torn between her responsibilities to her mother and her husband, getting little sleep, and feeling guilty about not fulfilling her husband's lifelong dream of traveling during their retirement years. Rose was exhausted, nearly requiring hospitalization for herself, when she saw an ad in the local newspaper about respite care services for older adults. She knew something had to be done about her situation, so she called to get information. Rose was able to arrange respite care for her mother for one week every month so that she and her husband could travel. The respite care service suggested that she contact her local social service department for additional help. She has also taken the opportunity with some of her free time to join a stroke club support group. Life is going much smoother for Rose since learning about these resources and accepting help. If only she had known sooner . . .

Using this Chapter

The resources available to older adults and their caregivers continue to grow. Specific telephone numbers and names of agencies will, therefore, generally not be listed in this chapter. Nevertheless, it is important to be aware of the types of services offered, how to locate them, and how to go about obtaining information about eligibility requirements.

INSTITUTIONAL SERVICES
IN HOME SERVICES
COMMUNITY SERVICES

Where to Start?

Families often find it difficult to obtain the necessary and appropriate professional help or assistance. Most people seem to hesitate to seek outside help. Initial contacts with community, state, or federal agencies can be confusing and discouraging. Many agencies have strict eligibility requirements, or many times useful services may not be available in your area. Although you may be faced with some of these problems in using the service system, here are some helpful ways to get started:

If your relative has been hospitalized or is under medical supervision, you can ask hospital discharge planners, hospital social workers, or physicians to direct you to appropriate services such as housing alternatives, preadmission screening, and home health care.

If your family member has not been hospitalized, it may be best to contact one of these sources for information:

- Your community's **Information and Referral Hotline**: 727-8538 for Duluth, or toll free 1-800-232-1300 for St. Louis, Lake, and Carlton counties.
- **The Area Agency on Aging**: 722-5545 for the Duluth area or toll free 1-800-232-0707.
- Your county's **Social Service Department**. Nearly every county has its own "Community Resource Guide for Services for Senior Citizens" which can be obtained by contacting the Social Service Department. Here are the telephone numbers for the Social Service Departments in the Arrowhead Region of Minnesota:

Aitken	927-3744
Carlton	879-4583
Cook	387-2282
Itasca	327-2941
Koochiching	283-8405
Lake	834-8405, or 1-800-642-3295
St. Louis	Duluth 726-2000, Virginia 749-7128, or 1-800-232-1300

- The **Human Services Directory** in the telephone book can be very helpful.

In order to effectively discuss your situation with the agencies you contact and to provide effective assistance to your older family member, you should consider these three areas:

- **Activities of Daily Living** (ADL). That is, determine what the older person can and cannot do. (See the boxed checklists in the next section.)
- **Limitations** of the older person. What physical or mental disabilities or handicaps does the person have?
- **Your needs** as a caregiver. How can you maintain your own physical, mental, and social well-being.

Activities of Daily Living (ADL's)

The Activities of Daily Living (ADL's) are the common activities all of us perform on a daily basis. Review the following checklist and rate the older person's limitations. She may be able to perform many of these tasks, just a few, or none.

Instructions: Put a plus sign (+) on the line if the person can do the activity by herself; put a checkmark (✓) on the line if the person can do the activity with some assistance; and put a minus sign (−) on the line if the person must have the activity done entirely by someone else.

ADL CHECKLIST

____ Getting dressed
____ Grooming
____ Bathing
____ Eating
____ Moving self in bed (bed mobility)
____ Transferring from bed to chair, etc.
____ Walking
____ Wheelchair use
____ Communication of needs
____ Toileting
____ Financial management
____ Household chores
____ Shopping
____ Transportation needs
____ Preparing meals

Instructions: Some other areas related to day-to-day functioning are listed below. Please rate the person you are caring for by writing "good," "fair," or "poor" next to each item.

GENERAL CAPABILITIES

________ The ability to know when to get medical attention.

________ The ability to take own medication appropriately.

________ Hearing.

________ Vision.

________ Need for physical rehabilitation (therapy).

________ Orientation: His/her awareness of the present environment in relation to time, place, and person.

________ Behavior problems.

________ Self-preservation skills: The mental judgment and physical ability necessary to cope with a changing environment or a potentially harmful situation (e.g., what to do if a fire starts).

________ Lives alone without daily contact.

Deciding if Help is Needed

Look again at the two checklists you completed in the previous section. Now, write a list stating each of the person's limitations as a need. For example, you may have marked down that the person is not able to do grocery shopping; therefore, you have "a need for someone to assist her with the shopping." Doing this for each item that is marked as a limitation will provide you with a list of needs for the older person. The list will be useful in determining the appropriate service or agency you would want to contact. It may also show you how much of your time is needed for your caregiving tasks.

Who Can Help the Older Person?

The potential sources for meeting the needs of the older person are (a) the older person herself, (b) the family, and (c) service providers (agencies). Let's look at each type of resource:

The older individual. Earlier, when you filled out the checklists, you determined what the older person can currently do for himself—an extremely important first step. It is important that you help the older person to continue to be as independent as possible within his limitations. Encourage him to do as many ADL's as is safely possible. This is beneficial in maintaining physical and mental well-being. It is difficult to stand and watch someone struggling to button his own shirt or to feed himself when we could do it for him so much faster. However, the increased self-esteem of being able to do for himself is worth the waiting. You need to use your own discretion in how much to do for your loved one, being careful not to do too much.

Family. Determine what each family member can do to benefit the older person. Calling a family meeting is a good starting point to get everyone concerned together to decide how much they can contribute to caring for the older family member. If you are the primary caregiver, look over your needs checklist and be specific to other family members about what assistance you need. Maybe some can help with visiting or being available for one hour or two to stay with your loved one while you run errands—maybe they can run errands for you. They may be able to provide transportation, meals, household chores, daily phone contact if that person lives alone, or financial assistance. As the saying goes, "No man is an island." We all need help. You need to be assertive enough to ask and then be able to accept the help.

Service providers. Determine what services are appropriate to meet your needs and the needs of the care receiver. These services are not luxuries. They may be helpful to you in performing your daily caregiving tasks. It is so important to utilize available resources to lighten your load and prevent "caregiver burnout." See Chapter 3 on *Managing Stress Effectively*.

Service providers are of three types: (a) in-home, (b) community, and (c) institutional. The lists in the following box will help you to match the needs of the older person with the most appropriate service provider. Be aware that all the needs of older persons can not always be met by a single agency. There may be certain services in the lists not available in your area. Although these lists are not exhaustive, they are representative of the services available for older adults and their caregivers.

IN-HOME SERVICES

- Chore Services (housekeeping, lawn mowing, snow removal, laundry, shopping, meal preparation).
- Homemaker Assistance.
- Home Delivered Meals (Meals-on-Wheels).
- Home Health Care Programs (e.g. Public Health Nursing Services, providing medical and nursing services).
- Home Health Aide (personal care services).
- Senior Friend (companionship).

COMMUNITY SERVICES

- Adult Day Care.
- Adult Protection/Vulnerable Adult Services.
- Befrienders (support program available through local church ministerial group).
- Caregiver Support Groups.
- Community Education.
- Community Mental Health Services.
- County Extension Office (budget counseling, nutrition needs, consumer skills).
- Food Service (Senior Citizen Nutrition Program, congregate dining—group setting, home delivered meals, food shelf, food stamps, food surplus program).
- Friendly Visitor, Telephone Reassurance.
- Housing Assistance (fuel and energy assistance, weatherization program).
- Income Maintenance (Medical Assistance, Supplemental Aid).
- Information and Referral Service.
- Legal Aid Service.
- Medical Equipment Rental.
- Postal Alert (U.S. Mail carriers report if older person is not collecting mail, or alerts help if daily routine is different).
- Pre-Admission Screening (evaluation of a person's needs & recommendation for the type of care needed).
- Respite Care.
- Senior Citizen Centers (activities, blood pressure clinics, flu shots, health education).
- Transportation (emergency volunteer driving)
- Volunteer Programs.

INSTITUTIONAL SERVICES

- Adult Day Care.
- Gerontology Case Management (coordinating and monitoring services in the home in light of changing needs of the older person).
- Hospice (for persons with a terminal illness and their families).
- Out-Patient Therapy (e.g., rehabilitative, physical, occupational).
- Respite Care.

The institutional services listed above may be available in clinics, hospitals, or nursing homes.

Contacting a Service Agency

Listed below are some suggestions which will be helpful to you when calling a service agency.

- Have your list of needs ready.
- Write down your questions.
- Have paper and pencil ready to take notes.
- Have relevant numbers/identification ready (e.g. Social Security number, clinic number, and Medicare number).
- Call early in the morning before workers go out into the field. Mid-week may be better.
- Be specific about the purpose of the call by referring to the limitations/needs list you prepared.
- Write down all the information given to you and the names of the workers you spoke with.
- Don't hang up until you understand what will be done or what you should do next.
- Follow up. Know what to do if it's necessary to call back again, or if you are referred to another agency, or if the results were not satisfactory.

Chronic Illnesses

Though the majority of older adults live healthy and active lives, many do experience one or more chronic (long-term) illnesses. Your first source of information should be the care recipient's physician who will be able to tell you in an understandable way what the disease is, how the person will be affected, what the treatment is, and what the expected outcome (prognosis) is. Don't hesitate to ask questions or to follow up with more questions if you don't understand. After conferring with the physician, you may want to contact one of the sources listed in the next box for more information. Also check the Yellow Pages in your telephone directory under the specific disease. You may also want to check your local library or bookstore for a book about the disease.

OBTAINING INFORMATION ON CHRONIC ILLNESSES

Alzheimer's: Alzheimer's Disease and Related Disorders Association (ADRDA) 1-800-621-0379.

Arthritis: Arthritis Foundation, 1-800-333-1380. (In Duluth, the Polinsky Center, 727-5083.)

Cancer: American Cancer Society, 1-800-ACS-2345. Cancer Information, 1-800-422-6237. (In Duluth, 727-7439.)

Diabetes: Diabetes Association, 1-800-ADA-DISC. You can also contact the local Diabetes Association or local hospital diabetes nurse-clinician. (In Duluth, 727-8989.)

Heart Disease: American Heart Association, 1-800-527- 6941. (In Duluth, 727-7297.)

Lung Disease: American Lung Association, 1-800-642- LUNG. (In Duluth, 726-4721.)

Multiple Sclerosis: Multiple Sclerosis Society, 1- 800-621-0379. (In Duluth, 727-5083.)

Parkinson's Disease: American Parkinson's Disease Association, 1-800-223-2732.

NOTE: Many communities have local chapters of the national associations, such as we have listed for the Duluth, MN area.

There are many other diseases that may be encountered. Again, specific advice should be given to you by the physician caring for your loved one. But don't hesitate to seek out information on your own, too.

Other Resources

Adult Protection. In situations related to abuse of older adults, contact the police department or the local county social service department.

Crime. If you are the victim of a crime (including consumer swindles) you should call 911 to reach your local police department. The agencies listed below can answer general questions and investigate complaints.

• Attorney General— Consumer Services Unit Hotline:	
in Duluth	723-4891
in Minnesota	1-612-646-7700
• Better Business Bureau	1-800-832-6428
• Insurance Information Center	1-800-642-6121

AARP. The American Association of Retired Persons (AARP) is an excellent resource for the caregiver. Listed in the next box are a few of the many books and pamphlets that are available. To order free AARP resources, send a request listing the title and order number to:

AARP Fulfillment Section
Box 2400
Long Beach, CA 90801

AARP BOOKS AND PAMPHLETS

Title	Order Number
• On Being Alone	D150
• Housing Options for Older Americans	D12063
• The Right Place at the Right Time	D12381
• A Handbook About Care in the Home	D955
• Eating for Your Good Health	D12164
• Miles Away and Still Caring	D12748
• Coping and Caring: Living with Alzheimer's Disease	D12441

To order copies of *Caregiving: Helping An Aging Loved One* ($13.95) write to:

AARP Books
Scott, Foresman & Company
1865 Miner Street, Dept. CJHL
Des Plaines, IL 60016

Newsletters. You can keep yourself informed about new developments related to caregiving by subscribing to newsletters. You might consider sharing the cost of these subscriptions with other caregivers in your community. Since a number of you would then be reading the same material, it is likely that you would want to discuss the issues, ideas, and strategies covered in the newsletters. Here are two that we recommend:

Parent Care, published six times a year by the University of Kansas Gerontology Center, presents useful information in an easy to understand manner. A one-year subscription is available for $20 by writing to:

Parent Care
Gerontology Center
316 Strong Hall
University of Kansas
Lawrence, KS 66045

Caregiving, published by the National Council on Aging, provides practical information to caregivers. If you would like to subscribe to this newsletter, send $25 to:

NCOA—Family Caregivers of the Aging
Department 5087
Washington, DC 20061-5087

Summary

The purpose of this chapter is to help you, the caregiver, recognize that assistance is available and to give you suggestions on how to find and contact the helping resources. This has been a general review of helping resources. Contacting your local **information and referral service** or **social service department** is a good starting point for locating specific agencies or resource people to contact. Learning how to assess the older person's needs is important so that you will be able to be more specific about the type of help you or the person being cared for needs. These services are not luxuries, but, rather, they should be viewed as necessities for helping you to be a more effective caregiver and to feel better about yourself and the important job you are doing.

RECOMMENDED READINGS AND REFERENCES

Many of the books listed here were recommended to you earlier, and others have been added that are also good sources of information. The complete information listed here can help your library or bookstore locate the books for you. We have included comments for many of these books to help guide your selection. The books without comments have been included because we quoted from them in the chapters or because much of the chapter information was drawn from them.

Chapter 1: What is in This Manual for You?

Mehrotra, C. M., Randolph, S. M., & Dietrich, D. M. (Eds.) (1984). *Instructional Manual for Parent Caring Program.* Duluth, MN: College of St. Scholastica.

This manual provides information for facilitators and speakers who wish to conduct educational programs for caregivers of older adults. A number of chapters from this manual were used as background material in preparing the new manual that you are reading.

Chapter 2: Being a Caregiver

American Red Cross (1979). *Family Health and Home Nursing* (7th ed.). Garden City, NY: Doubleday and Co.

This inexpensive book may be useful in learning various aspects of basic home nursing skills and practical issues related to caring for the chronically ill.

Horne, J. (1985). *Caregiving: Helping an Aging Loved One.* Washington, DC: American Association of Retired Persons. Glenview, IL: Scott, Foresman.

This excellent book is written for individuals providing care to a frail older adult. It covers the full range of relevant topics in an accurate, easy-to-read fashion.

Gibran, K. (1971). *The Prophet.* New York: Alfred A. Knopf.

Subcommittee on Human Services of the Select Committee on Aging (U.S. House of Representatives). (1987). *Exploding the Myths: Caregiving in America.* Committee Publication No. 99-611. Washington, DC: U.S. Government Printing Office.

Vulnerable adults act. (1980). *Minnesota Statutes,* 626.557.

This Minnesota law defines your responsibilities as a "caretaker", definitions of abuse and neglect and various reporting procedures.

Chapter 3: Managing Stress Effectively

Ardell, D. B. 1977). *High Level Wellness.* Emmaus, PA: Rodale Press.

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> This is an introductory level college textbook on the psychology of aging from young adulthood through old age. The book provides detailed discussion of most of the topics from chapter 9, in addition to topics that are not in-

cluded in this manual. Topics on the psychological development of young adults and middle-aged adults will also have personal relevance for young and middle aged caregivers.

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Acknowledgments

We are indebted to a number of individuals who have provided us with valuable assistance in the preparation of this manual:

- Mary Robillard and the members of the Arrowhead Regional Development Commission's Advisory Committee on Aging, who have provided us with continued support in all phases of our work with caregivers.
- Project Advisory Committee members for helping us in selecting topics and for reviewing various drafts of the chapters: Mildred Apuli, Yvonne Carl, Katherine Hynes, Cathie Hyopponen, Beth Koski, Bruce Riplinger, and Joyce Seppo.
- Tom Boyd who prepared all of the illustrations drawing upon his life experiences, insights, and artistic abilities.
- Karen Bernsdorf who, as always, assisted us in so many different ways.
- Joan Wainer for reviewing the literature, contributing to various chapters, and assisting in the editing process.
- Steven Zarit who promptly reviewed the manuscript and gave useful suggestions.
- Michael Smyer for providing advice during the initial phase of this project.
- The chapter authors for sharing their expertise with the readers by preparing the chapters and for their patience with us during the editing process.
- Our colleague, Dan Johnson, for helping us with arrangements for publishing the manual.
- Joan Henrik and her associates at Westmoreland, Larson & Hill for their enthusiasm and creativity in preparing the camera-ready copy for printing.
- Richard Fuller and his colleagues at Arrowhead Printing for printing the manual.